

NATTERING WOMEN?
THE PSYCHOSOCIAL FUNCTIONS OF CANCER SELF HELP GROUPS

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ABSTRACT

This work arose from a concern about the psychosocial aspects of health care. Although self help groups are one means by which information and support can be offered and received, there are few studies of health self help groups in Britain. The available literature suggests that self help groups are complex organisations which are difficult to define and categorise. This study adds further confirmation to that.

This research follows an ethnomethodological approach and provides an in-depth study of six cancer self help groups. Data were gathered from interviews with group members and associated professionals, and from participant observation of group meetings.

Women's experience of the diagnosis and treatment of breast cancer suggests that they are poorly informed and receive little or no support within the formal services. They go to self help groups with little information about them and hold unrealistic expectations of what the group might offer. Participation in groups occurs at a variety of levels and frequently over a long period of time. The groups provide women with practical and social support and act as a means of empowerment to enable them to accommodate their illness into their lives and help to realise their health potential.

The interviews with professionals suggest that they were aware of the benefits and possible drawbacks of self help. However, few had fully considered the nature of self help, and professional involvement. Groups were keen to develop good relations with professionals as one means of legitimisation yet wished to maintain their own integrity and control. This enabled a shift in the normal, individual social relationship between patient and professional.

Several policy issues in relation to both the delivery of health care for people with diagnosed cancer and about the organisation and function of self help groups and their interactions with professionals are discussed. In particular the availability and nature of information and communication during diagnosis and treatment of breast cancer requires review. Self help groups are one way this might be facilitated. They are, on the whole, complementary rather than a direct challenge to mainstream medical services. They maintain a dynamic relationship with formal services, but generally attempt to work alongside local professionals. They provide a cost-effective psychosocial support which is unique. They provide considerable potential to advance a 'whole person' approach as envisaged by the World Health Organisation and it is in the interest of the Health Service to promote their development. Any support from medical and social services will require workers in the field to reassess their own practice and involvement with groups.

"I don't know what you think you'll find doing this (research). They're just a bunch of nattering women - they might as well be standing, looking over the garden fence."

Medical consultant

DECLARATION

With the exception of those mentioned overleaf, this thesis has been composed by me, and the work is my own.

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CHAPTER 1 : INTRODUCTION AND LITERATURE REVIEW

INTRODUCTION

This work arose from a concern about health care for women. The study of cancer self help provides an opportunity to look at several areas of interest. The psychosocial aspects of health and illness had been recognised by the women's health movement which had also focussed attention on the delivery of services. Self help, as well as an area of interest in itself, is one response to that. Self help groups emphasise their psychosocial experience, professionals focus on medical aspects of health care, so their interactions highlight these two approaches. The study of cancer self help groups raises issues about health care and its delivery, about self help groups as organisations, and about professional practice in relation to self help. These are particularly important following recent policy decisions outlined in *Working for Patients* (1989) and *Caring for People* (1990).

The emergence of the women's health movement has its origins in the practice of self care and a social view of health. These origins and much of the guiding principles are shared by self help groups. These links seem to have been neglected in the self help literature. The social/political elements of health care and illness, which were largely ignored by the medical profession, stimulated the rise of the women's health movement. This raised general issues about health care, eg impersonal procedures, communication difficulties etc., although, undeniably, women were more affected in some areas of health care than men. This recognition was taken up in different ways by different groups; some professionals attempted to consider the whole person, moves were made to empower the individual and the medical curriculum included psychology. One reaction was self help, and working collectively. Self help can be seen to share its origins and concerns with the women's health movement, and to be precipitated by it.

Reading any historical account of health and illness (eg. Porter and Porter 1988) makes it clear that people have always been interested in maintaining their own health, and preventing disease. They were doing this long before the scientific advances of the 18th century, often with the help of local women and men who had developed some understanding of physical functioning and possible remedies. Indeed self care was necessary; there was no other option.

During the 18th and 19th centuries health care became increasingly the prerogative of the physician, who with his (sic) 'superior' (technical/scientific) knowledge came to undermine the confidence and knowledge of ordinary people (experience based and non-scientific) in dealing with their illness. Medical experts began to restrict who might be involved in health care. Thus the use of a medical instrument, the forceps, was restricted to "doctors". As it was forbidden for women to be so educated, they were effectively excluded from a profession they had held for centuries (Ehrenreich and English 1974).

Many writers have documented the rise of the women's movement and in particular the women's health movement (eg Marieskind 1976) relating it to a reaction against patriarchal views of women and linking it with the women's movement in general. Other authors see it as a more general move towards consumer health (McEwan et al. 1983). It is not intended that this work here should be a critique of the women's health movement or an analysis of subsequent events. However, the critique that women offered of health care and its delivery are of relevance to self help, and important for women's health self help groups. Both are concerned about how health care is best achieved and by whom. The issue remains about the individual's contribution and its acceptance by the medical profession.

Many people other than the women in the consciousness raising groups benefited from highlighting women's oppression within the health care model currently in operation. In some ways the impact of these changes can be seen in the collectively produced Boston Women's handbook - *Our Bodies Ourselves* (Boston Women's Collective 1989) which was published internationally and is still an invaluable source book, kept updated even years later. People generally were becoming aware of the inadequacies of the health care system.

This movement was mirrored in Britain, but less dynamically. This may have been mediated by the National Health Service, which still managed to provide a health care service that remained free at the point of delivery - one of the demands of the American women. That this masked huge inadequacies in health became clear in the Black Report (DHSS 1980) and little has changed since (Whitehead 1988). Certainly those issues that concerned women in the early 70's are still around. The attitudes and discriminations that provided the impetus for the first British Well Women clinic in Manchester in the early 80's remain (Foster 1990).

Writers in the field of sociology of medicine have acknowledged the limitations of medicine. Parsons (1952) recognised that medicine could be seen as a means of social control. Illness, as a deviant behaviour, and its associated "sick role" could be controlled by medicine which not only defined the 'illness' but could define who was and was not sick. However the concept of the sick role is limited in its application to any 'self cared' illness, as well as its relevance for chronic or neurotic conditions.

Illich (1976) points out that medicine has failed in its initial aim, and that the doctors' interest has "shifted from the sick to sickness". He concludes that "Medical nemesis is the negative feedback of a social organisation that set out to improve and equalize the opportunity for every man to cope in autonomy and ended by destroying it." It could be argued that the prime role of self help groups is to empower people in such a way that they inadvertently resist the institutionalisation of medical practice. They shift the focus from the illness, to the individual. Goffman (1961) highlighted the power of the institution. Technologies and procedures are aimed at maintaining the institution, not primarily the health and well being of the individual.

The concealed iceberg of dysfunction (Goldberg and Huxley 1980) has overwhelmed the resources that are available within the present (or indeed any) economic set up, the policy makers have moved back and out towards the "community" again. Several people are now being pushed back into this "community" with little change in availability of resources. This most directly effects people with mental handicap and mental health difficulties, for the moment.

Responsibility is being pushed back onto individuals not only to adjust their lifestyles, but to look after their own illness and that of others. Resources, it seems, are scarce, and may become more so. Professionals are being pushed to account for their time, and to produce figures to justify their service. This is not necessarily conducive to good communication, nor does it allow for a wholistic approach. As services are pitted against each other for the limited finances, the justification lies in numbers, rather than quality of care; in short term goals, rather than longer term benefits. There is a danger that visible technologies will obscure the importance of more elusive psychosocial issues and outcomes.

The women's health movement had placed health care in a social/political context, and so examined its delivery. The government continued to put emphasis on individual behaviour and push aside political and environmental issues. The DHSS 1976 consultative document "Prevention and Health: Everybody's Business" clearly emphasises individual behaviour as a major contributor to health/ illness. But the tone blames the victim, rather than encouraging better self care and interaction with professional experts. The document states that "Perhaps the most difficult diseases to prevent are those which depend on individual behaviour" and

"The role of the health professionals and the government is limited to ensuring that the public have access to such knowledge as is available about the importance of personal habit on health and that at the very least no obstacles are placed in the way of those who decide to act on that knowledge." (DHSS 1976)

No means by which people might be helped to change is included, or any notion as to why these patterns of behaviour develop in the first instance (eg tobacco and cigarette advertising). This emphasis on lifestyles was also evident in a more recent document from an independent multidisciplinary committee (Smith and Jacobson 1988). This document intends to develop a 'Strategy for the 1990's', but there is no mention of self help or collective action. Although Ilona Kickbush, one prominent writer in the field of self help at the World Health Organisation, is acknowledged, no contribution is evident in the text. The issues about responsibility for health remains high on the agenda of the current government, although the emphasis seems to be on cost rather than care (Caring for People 1989, Working for Patients 1990).

Self help may be seen as a cheap alternative to conventional medicine, but cheap for whom? Certainly not for participants in terms of time, energy and sometimes money. In a health service that is increasingly held to financial account, this may be an important question.

There is also the danger that self help groups may be seen as capable of taking over what is currently an aspect of professional work and responsibility. Groups have their limits, and, on the whole, do not aim to supplant formal services. As Mitchell (1982 pp167-8) points out

“What we want in industrialised countries today is not to have the burden of healing and care returned to us without support from the health service, but to have sufficient knowledge to have the confidence to deal with minor illness, to meet NHS full-timers on more equal terms and to challenge what is making us ill.”

This could be a useful summing up of the main aims of health self help groups. The author recognises that the main struggle for health takes place outside the health service and that this has to be acknowledged for any realistic planning of services. Self help groups are one of the organisations that exist outwith the formal services. However the same author (Mitchelle 1982) warns of the danger of seeing self help as a way of saving money.

It is within this climate that an examination of self help is deemed necessary, indeed essential. Not only might self help be co-opted as a cheap community resource, but its function as an alternative model of care may be undermined. If people are going to take on responsibility, how can it be done well, how can they regain power over their own lives, and how can they decide when to confidently seek out the limited health resources, and to avoid invasive investigation and prescriptions. Some may also ask, how can they let their voice be heard about the inadequacies in provision? These questions have always arisen within self help groups.

Overall, the women's health movement highlighted several issues about the social and political nature of health and health care. Many of these concerns are shared by self help groups. Some of the general issues of participation in health care were pursued in various ways by different professional and non professional groups. Health self help groups in particular are concerned with the social dimension of health care, with the appropriate delivery of service, and with the empowering of individuals to achieve optimum health. They provide a challenge to the dominant medical model of health, which took little account of social factors in health. To some extent they, like the early women's groups, have had to face the difficulties of providing a challenge to a dominant professional group.

However there remain differences between the women's health groups as envisaged within the women's movement and health self help groups in general. In particular is the emphasis on fundamental changes in services. The women's movement sought not to supplement the health care service but to radically change it from its patriarchal views and practices in relation to women. They attempted to provide services that (some would argue) were already available. Health self help groups seldom have these stated aims. They more often attempt to provide what they find is not available within the formal services, although they do not all appear to arise from a direct criticism of service deficit. Nevertheless, the attempt to provide something additional still takes as its fundamental principle the social aspects of health,

and thus they provide an alternative to the predominant medical model. This in itself may be perceived as a direct challenge to medical authority.

The self help, which is of particular concern here, is a type of mutual aid and self care - where a reciprocal relationship evolves around a health/illness issue. Self help groups aim to reduce isolation through sharing experiences and using education and information to facilitate an optimum health and social future. They also provide a forum for a different type of interaction with professionals. People seek out self help groups following their experiences of diagnosis and treatment of cancer, looking for information and shared support from others.

In this work the framework of recent self help literature in Europe is examined, with particular attention to accounts of health self help groups and specifically self help initiatives for people with diagnosed cancer. The workings of self help groups and their evaluation in recent years had given way to a focus on wider organisational structures (ie clearing houses) that are seen to support self help at regional and national levels. The policy advances of the eighties seem to be based on fairly limited empirical evidence about the actual advantages and disadvantages of specific self help groups. There appears to be very little information available about these groups, their actual mode of working or involvement of professionals.

The current study attempts to address these issues, providing some evidence about the functioning of six health self help groups, the views of their members and the professionals involved with them. It was clear that people came to the groups through a wide variety of experiences, and that groups managed to function to meet disparate aims. They struggled for existence - and often validated themselves through their relations with professionals, but remained cautious about close professional involvement.

Professionals involved with the groups held a general view that the groups were 'a good thing', but few were able to fully shed their professional fears of accountability, nor could many contemplate relinquishing professional control. For most professionals their view of the future for these groups included professional leadership or closer involvement with professionals. There seemed to be little understanding of how this might affect the nature of the groups. A very few professionals expressed the view that the groups should act more to pressure the existing services in a way that they, as professionals within it, felt unable to do.

Some policy issues are discussed, particularly the role of the groups in highlighting and facilitating communication with professionals. The possible relations of self help groups and professionals is open to discussion.

This chapter so far has outlined the development of medicine and its effect on women. This remains one of the main precursors to the women's health movement. It clarifies that many of the issues of concern that the women's health movement raised are also those that informed self help. Both the women's movement and self help groups, in their own ways,

challenge the predominant medical model of health, which takes no account of social factors in health. The current situation with health care in Britain, makes it particularly important that this challenge is recognised. This places further emphasis on the importance of seeking new empirical evidence about self help groups in health.

SELF HELP

Self help and self care require differentiation. Several authors have clarified self care as looking after oneself, or of others, on a day to day basis. Contrary to the picture sometimes offered by the media, many people adequately self care, and will attempt to do so before they visit the general practitioner (GP), (eg Stimson & Webb 1975, Blaxter and Paterson 1982). McEwan (1983) indicated that people will self medicate when they feel the illness is trivial, or they would be inconvenienced by going to the GP. He states other reasons, more related to the doctors than the illness viz, seen to be wasting doctor's time, feeling that nothing can be done or poor past experience of doctors leading to lack of faith. One further suggestion was a fear of the diagnosis. It seems therefore that people do recognise the limitations of medicine, that they are aware of the attitudes of some GP's and they base their behaviour on their own experiences. Doctors are, in fact, doing a good job in keeping people away from the clinic.

There is a distinct literature on self help that takes the helping of people mutually and collectively as its main focus. Although people are assumed to be helping themselves when they are self caring, self help is understood to be a particular way of looking after oneself that also may help others. People are seen to enter into self help with a more general aim towards mutual aid, enabling and self advocacy. Most of self help then, is done in groups and it seems to have been around for some time.

One of the first reference to self help is Samuel Smiles whose book (originally published in 1858) outlined some of the friendly societies and mutual aid organisations at that time (Smiles 1958). However the orientation of these organisations seems to have been less philanthropical than the self help that we understand today. Similarly Kropotkin (1902) a Russian revolutionary and scientist, published a series of articles in England in 1890 detailing his views of the need for collaborative action. His thesis was a response to the Darwinian theory of evolution. Kropotkin proposed an ethical struggle whose vehicle was the tribe/ family/ group that led to a "loftier evolution".

The importance of self help has been emphasised in recent years with a move towards community care. Its importance in the realm of primary care was emphasised during the initial push toward the WHO 'Health for all by the year 2000' initiatives. It's long history is easy to forget in the face of more recent publicity.

"Self help is grossly misperceived if it is seen merely as a temporary expedient or passing fashion, since self help is, of course, as old as human history. People have always banded together to solve their common difficulties and promote their mutual interests..." Robinson (1980)

Currently in Britain there are thousands of self help groups listed in various directories. There are also a plethora of publications both in Europe and the USA, which offer a diversity of definitions, typologies and analyses of the phenomenon of self help.

DEFINITIONS

Many authors begin with an attempt to define self help, and self help groups. At least 30 such definitions have been identified for this work. Overall it seems that the extensive and multifaceted nature of self help is difficult to define. Definitions of self help groups change to suit the specific needs of the research/ author, or take as their reference one of the more encapsulated or simple definitions currently available.

A selection of definitions of self help were taken from the most prominent literature in the field in order to identify the most commonly occurring features/characteristics. Themes that emerged concerned the actual problem focus of the groups, their activities and the structure of the group. Most authors focussed on one or a combination of these aspects of self help groups.

Many identified self help groups as problem or need related. Some identify the the problem or need as residing in the individual eg

Knight & Hayes (1981) : "members share a common problem"

Tracy & Gussow (1978): Self help groups give "assistance to members in dealing with adaptive problems resulting from disability due to illness, disease, or other health related disorders."

Kleiman et al (1977): "people sharing common needs and experiences"

Others locate the problem within society (Levy 1976). This seems to depend on the type of group being studied. All appear to assume that the groups focus on a difficulty or need that is not being met.

The structural aspect of groups as organisations receives less persistent attention. Some (eg Gartner and Riessman (1977) Killilea (1976)) appear to imply an organisational structure for the groups without making this explicit in their definition. Others (Knight and Hayes 1981) have criticised Killilea in particular for this omission. Most of those authors making reference to this aspect of groups recognise the self management, non-profit making orientation of most self help groups, eg

Brimelow & Wilson (1982a): "Self management"

Katz & Bender (1976) : "Self help groups are voluntary small group structures.."

Hatch & Kickbush (1983) : "Mutual benefit associations are those where the main beneficiaries are the members, they are not business concerns, service organisations or commonwealth organisations."

Knight and Hayes particularly emphasise the voluntary (non-statutory, non-profit making) element, and point out that groups also exist without outside funding. This reflects not

only their critical review of Killilea's definition, but also their own community focus. Others include the groups' orientation to professionals eg

Deneke (1982): "no or little involvement of professional helpers"

Levy (1982): "...relies on own members as peers, professionals are involved only at the groups discretion."

However few use the groups' relations to formal services as a defining characteristic. This may be because this area is under researched and unclear. Some indicate that the groups originated because of an unmet need eg.

Williamson (1983): "This type of disadvantage may vary widely but each is characterised by a need for help which is not available in any existing service, professional or otherwise".

Sidel & Sidel (1977): "Self help groups deal with unique problems that cannot be dealt with elsewhere."

Kleiman et al (1976): "...because their needs cannot be met within the traditional system."

On the whole, these authors fail to define the groups' subsequent relationship to the formal services. Only Killilea (1976) offers the distinction of groups which work with, next to or opposed to the formal services.

The activities of self help are seen as wide and divergent. However the emphasis remains on shared experience and mutual aid, with some authors highlighting the helper principle (Riessman 1965,1976) as a major aspect of self help eg

Killilea (1976): "The helper principle. Where people help others with a common problem, the helper may benefit more from the exchange"

Knight & Hayes (1981): "The helper-helped role is shared"

Mantell (1983): "An exchange between helper and recipient represents the prototype of the self help model."

However, in practice, although many authors prefer the term 'mutual aid' rather than self help, few groups refer to themselves in this way. Most prefer the term 'self help'. Knight and Hayes (1981) for example found that none of the community groups they studied in London used 'mutual aid'.

These three aspects of self help are the most commonly referred to in a definition, viz. problem or need oriented, a peer/equality related structure and operating mainly through mutual aid.

Other aspects of the definitions of self help in the literature include reference to shared experience as a basis, as well as a process within the groups. It may be artificial to differentiate it from the issue on mutual aid, as it may be impossible to do one without the other. Many authors assume this as part of self help/mutual aid eg

Levy (1976): "...a shared common area of life experiences and problems."

Gartner & Riessman (1977) : "Indeed this may be the single most common denominator of the various types of self help groups that I have looked at here ("anonymous" groups eg Alcoholics Anonymous)- namely, that the role of the person who has already lived through the experience is critical for helping others."

Mantell (1983) : "The primary qualification for belonging to the traditional group is personal experience with the dilemmas shared with the group members."

Related to this is the notion that as people share similar experiences and engage in mutual aid within an organisation that it is egalitarian, that the participation of members is fairly equal. There is an emphasis on active participation.

Linked with this is a recurrent but not pervasive notion that self help groups articulate an ideology of change. This occurs in several definitions eg

Brimelow & Wilson (1982b): "...changing or dealing with problems in self or society."

Katz & Bender (1976) : "...bring about desired social and/or personal change."

For some the focus is a change in society (eg Jones et al 1984) or/and the individual (eg Katz & Bender 1976). Toseland & Hacker (1982) use 'coping' rather than change, although it may be argued that one presumes the other.

Tied in with the idea of change is the notion of action, generally collective action eg

Killilea (1976) : "Constructive action towards shared goals. Groups are action-oriented with a philosophy that members learn by doing and are changed by doing"

Some authors (eg Mantell et al 1976, Mantell 1983) highlight the specific activities of the groups (advice, information etc.).

In summary, most of the definitions of self help groups in the recent literature are unique - there seems to be no consensus on a definition of this phenomenon. However most authors refer to three main dimensions of self help's orientation, structure and activity ie problem or need oriented, equality of membership and mutual aid activity. The dimension of groups' relationship with professionals or formal services is seldom addressed directly. However this seems to be a large part of what differentiates these groups from other organisations.

As with all attempts to define a disparate and multifaceted phenomenon, many of the definitions offered fall down in practice. As with attempts to offer a typology of groups, the theory and the reality do not match. This is evident in the literature where each new study produces a new definition. In the current work, briefly taking the three pervasive elements found in the definitions offered in the literature in relation to cancer self help groups indicates how far the ideal can vary from the reality.

Although it was certainly the experiences of most cancer self help group members that brought them to the groups, each member, and each group might focus on a different aspect of

that experience and therefore offer a different problem focus. In one of the groups studied in this work, there were also people who did not have that experience, but were still regarded as members. In the groups studied here there was not an equality of membership or of practical participation although that might have been the articulated principle. In addition each group had a different level of professional involvement. Some of the groups emphasised their educational and information giving functions as much as mutual aid. And although mutual aid was evident in all the groups studied, not everyone used the groups in this way. Some members did not engage in much personal interaction in the group, and came along mainly for information only.

These findings are not unique, but reflect the experience of other researchers. Richardson discusses them briefly in her paper "The Diversity of Self Help Groups" in Hatch & Kickbush (1983). It is worthwhile quoting a passage in full to illustrate how these definitions seem to arise from untested theoretical constructs, and how they lack a basis in empirical evidence.

"Despite the apparent heterogeneity of the problems on which they (self help groups) are focussed, these groups are thought to conform to a roughly similar pattern. There seems to be a clear image of what constitutes a self help group in the public mind. They are composed of people with a single common problem who have joined together to provide a common solution to it. Everyone is fully involved and committed. They work by members giving help to one another on a mutual, reciprocal basis. They show, in short a common framework, whatever the problem to which they are devoted.

The aim of this paper is to demonstrate that this picture of mutual aid groups is much too simple. It may prove correct in some cases, of course, but the reality of what self help groups do, why members join, and what they get from their involvement is much more complex. "(Richardson op cit)

It may be argued that even Richardson is overstating the case for the consensus on self help group definition. She also ascribes it to the public rather than researchers and writers, whereas no study so far has tapped public images of self help groups. In general, however, her point stands, that the pure self help group seems to be rare. Her own British work clarified the situation in relation to social self help groups, through a study of nationally organised local groups. She makes a presumption in her conclusion that other groups (ie 'medical groups') will be more or less the same. This study attempts to view "medical" self help groups, using a variety of groups focussed around one issue, and including unique small local groups as well as those forming part of a larger organisation.

Overall there are a variety of working definitions devised by different authors in an attempt to limit and focus their work. Perhaps self help groups are too divergent for a single definition to encompass all. Much of the difficulty arises from the relative fluidity and changing nature and focus of groups (which is in practise one of their strengths), as well as the relative lack of information and understanding of self help. It may well be that an unsatisfactory definition of self help has to be tolerated of this seemingly simple, but very complex phenomenon.

TYPOLOGIES

As well as struggling with defining self help groups, many authors have attempted a typology. As the strength of the product of this type of exercise lies in its explanatory value and usefulness, this area will be reviewed with direct reference to cancer groups. Each typology will be critically reviewed in the light of an understanding of self help, and also in relation to its usefulness for clarifying the six groups in this study.

Many of the classifications offered focus on the problem that the group is addressing. Others have attempted a typology that takes the processes of groups as its main criteria. While the two are undoubtedly related, any one group can be differentially classified within the two systems.

Typologies focussing on the problem that brought the group together may be fairly simple, such as that presented by Levy (1982) who offers

- 1) physical difficulties
- 2) mental and emotional difficulties
- 3) problems of social status.

This sort of concrete focus is fairly clear cut, although the actual orientations of some groups may make them difficult to satisfactorily classify using this typology.

Any breast cancer group undoubtedly has a physical problem to contend with, but it also has emotional, social and mental health aspects to it. Some might also feel that a major impact of the disease to be addressed in the group context is the affect that it has on highlighting women's social status. Thus the approach of the group may be very poorly reflected if it is simply categorised under "physical".

Bean's (1978) analysis, based on Alcoholics Anonymous (AA), offers categories of crisis or permanent/fixed conditions, as well as a third encompassing habit/addictive/self destructive conditions. Although these may seem to be exclusive and a little more sophisticated, again if used for cancer groups, they do not provide a useful distinction between types. Cancer self help groups may well deal with the crisis of the disease, but it then becomes a fixed or chronic condition that has to be faced over and over again.

Gottlieb's (1982) three point typology offers an apparent move from a focus on the problem to an attempt to look at the working of the group. He suggests that groups are organised around

- 1) loss / transition
- 2) one step removed
- 3) stress / coping / support.

Within this, the first conceptualises the typology in terms of the problem focus, then the relationship of the individual to the difficulty experienced, while the third emphasises what the group offers. Such confusion cannot be helpful.

Interestingly typologies offered by earlier writers in the field focussed more on the processes of the groups, such that Levy's (1976) four part classification proposed,

- 1) conduct reorganisation / behavioural control
- 2) sharing stressful predicament
- 3) survival orientation
- 4) personal growth.

It may be argued that the latter two emphasis group aims rather than process. Using this to typify cancer or health groups, the difficulty again arises that although each group may be classifiable temporarily in an exclusive category, over time this may become redundant. There may be an apparent re-orientation in the group, and in the emphasis for each individual within the group. Some groups would also argue that personal growth is always part of their functioning.

It seems that only Gartner and Riessman (1977) include a category for 'prevention'. This may well have been ignored by other authors through the emphasis that has been placed on the problem orientation of the groups (highlighted in the section on definition).

Tracy and Gussow (1976) widen the typology a little using only two classes of inclusion. These emphasise the way in which the groups operate, rather than the process within the group. Groups are seen as either providing a direct service (for whatever problem and in whatever way) or emphasising research, education and legislation. It was noted by the authors that these two functions were not mutually exclusive, thus diminishing the usefulness of the system.

Few authors have tackled a dichotomy that was introduced in this field by Sagarin (1969) who classified groups only on one dimension, ie whether they attempted to help members conform to society or to challenge or change it. This seems to be important given the debate in the literature on self help as a social movement, and the apparent entrenchment of professional workers in characterising groups as weak and useless or overbearing and harmful (Leiberman & Borman & assoc. 1979 p407).

The notion of self advocacy occurs more often with those writers whose main experience is in the field of mental health. Katz and Bender (1976) include self advocacy in their typology, presented in terms of inner or outer focussed groups. Their particular work on deviance leads them to produce group types that indicate relations to society as their main axis of differentiation. They perhaps recognise the complexity of the task (or else give up on the exercise) by their inclusion of a fifth (mixed) type.

It might be argued that self advocacy is a way of changing, or challenging society, so that change is brought about by individual change, rather than by challenging society as a whole. There is some strength in the argument that these groups, by their existence challenge the existing services/society/mode of practice. Often this may not be something that they recognise, and is not reflected in their population, activities or their interactions with professionals.

It is interesting that the typologies offered cluster around the same basic themes as the definitions of self help groups (problem focus / processes in groups). However, where some attempt was made to include the structures of groups as part of their definition, there seems to be no attempt to type groups according to structure. This may be because the structures of groups do not differ enough to produce a useful typology. It may also be because the structures within these groups are poorly understood, and therefore the information is not available upon which to base differentiating categories. Alternatively, the structures of the groups may be too complex, or varied for a useful typology. In the literature pertaining to typologies of groups their relationships with professionals generally receives little attention.

There appear to be difficulties with each of the typologies offered so far in the literature. They are usually developed to refer to only a limited selection of self help groups. An operational typology is presented that encompasses mainly those groups under scrutiny at the time. Using the single example of cancer self help groups illustrate that these typologies, focussing on the problem, the process of the group, on its mode of operation or its ideology, do not adequately differentiate groups or are too narrow to be of any general use. They are not adequate to account for the phenomenon, the complexities of which will be argued in this thesis. Neither do they clarify or differentiate between the groups in such a way as to provide exclusive or meaningful categorisations. Where they do differentiate between different types of self help groups they lose important features of the group.

It can be concluded that no adequate typology of self help groups has so far been offered in the literature. This work does not aim to redeem this, but does attempt to add to the empirical evidence about self help on which any future categorisation may be based. It is only with detailed study that the richness, and thus the connecting threads, in self help can be distinguished.

This thesis takes a wide empirical definition of self help groups, ie those which are focussed on the specific needs/difficulties of breast cancer, whose structure is at least *presented* as more or less egalitarian, and whose activities are mainly mediated through self help and mutual aid with the sharing of experience. These groups once identified were quickly and easily differentiated by their organisation and their relations with professionals.

SELF HELP AS A SOCIAL MOVEMENT

Self help groups have been referred to as a social movement (eg Tracy and Gussow 1976). Schiller and Levin (1983), in their analysis of self care as a social movement, identify what they consider constitutes such a movement. They offer one definition of a social movement as a phenomenon where people join in collective action in a structured or identifiable way to articulate ideologies and global goals - the strategies adopted being aimed at changing or resisting a change in the social structure. While they see this as too general, they see others as too narrowly focussed or concentrating purely on psychological dynamics. They weigh self care up against the most salient characteristics of a social movement, and find it lacking. Thus they see self care as lacking a consistent ideology, without sufficient common purpose. They note that self care has not followed the social movement pattern of a structure that moves towards institutionalisation. Although self care seems to take some definite action, this is not within a clearly developed strategy. They therefore feel that self care could be part of a larger social movement eg citizen participation, but falls short of constituting a social movement within itself.

Back and Taylor (1976) are certain that self help does constitute a social movement using the theoretical basis of Blumer (1969) to conclude that groups do move to challenge and change society. Indeed there were some indications that self help upheld the status quo and thus may be regarded as institutionalised. Katz (1979) challenges previous writers who suggest that self help groups perpetuate inadequacies in formal services. He gives empirical examples of groups that both challenge and change public policy.

However, others have been more cautious in their conclusions. Although participation in health care is seen to have increased in recent years, the evidence of this and other indices of social change are fairly limited. Toch (1965) pointed out the change was to be in the members, in both a clinical and a social sense. Katz and Bender (1976) believe that as self help changes individuals this affects the larger society, and thus more major change is brought about. Trojan (in Hatch and Kickbush (Eds) 1983) documents the social changes that accompanied the emergence of self help in France up to the 1980's. Others (eg Robinson & Henry 1977, Katz and Bender 1976) suggest that groups help people cope within the limits of what is on offer rather than challenge, and this minimises their effect on policy.

The question is whether the self help groups that exist do provide a new model, and how effective is their influence? How aware are professionals of the movement, and how have they themselves moved to accommodate it? Hatch and Kickbush (1983) suggest that there has been a two way movement both from self help groups to professionals and from the professionals to the groups. Some actually use the pressure group activity as part of the definition of self help (Killilea 1976).

The nature of the professionals who set up such groups may be such that the group acts as a vehicle for them to express their own difficulties with the constraints on them because of their professional role (see chapter 6 on professionals). Indeed the role of professionals and the relation the group has with the formal services is crucial to any estimate of the pressure group functions of self help. This in turn offers some estimate of their contribution to any social movement. The amount of emphasis that groups place on the wider social issues, the politically mediated climates in which they exist and their attempts to change or challenge these may be a more complicated issue. It may also relate to the problem(s) that the groups focus around.

The argument in this work reflects self help groups among those vulnerable through a life threatening disease, and their understandable acquiescence to a profession that offers them some expertise and therefore hope in the fight against it. The construction of illness and its causes are factors that influence the political and pressure group activity of cancer groups. Their lack of confidence in their own health care make it difficult to challenge the institute of medicine. They recognise the social dimension of the illness, and that is what they, on the whole, set out to deal with. As only an estimated 5% of people (Lieberman & Boreman 1979) seek help from a self help group how far can this small number initiate a social movement? There is no direct evidence that this figure holds for cancer self help groups. The question does arise as to how such a relatively small group of ill people can be seen as so challenging to the institute of medicine.

Crawford (1980) identified a complete cycle. He made reference to victim-blaming in the self help movement, where little reference was made to environmental factors when discussing health issues. Crawford argues that as self help did not assume social control responsibility, the re-emergence of medicalisation was likely. He clearly saw self help as a challenge to professional medicine .

“First the women’s and self help movements have undercut professional authority and raised the issue of medicalisation.” Crawford (1980).

This concern is reflected in a more recent Lancet editorial, widely attributed to Michael Marmot (Lancet 1981), which states that the dangers in placing so much responsibility on individuals in self help for their health care might lead to placing individual responsibility for illness on them too.

Whether the same could have been said about the original self help clinics of the women’s movement is difficult to say. Lieberman, in Lieberman and Boreman (1979, Ch 9) suggests that even the women’s consciousness raising groups were more concerned about personal well being and women’s issues than attempting to induce political or social reform.

Although so many authors in the field accept self help as a social movement, the issue is not entirely clear. The degree to which different self help groups offer a challenge to

medicine or to society varies greatly. However, in the area of health care the women's movement certainly offered a major challenge, and in some areas attempted to supplant formal provision. Health self help groups may be less able to do so, even should they wish. Few groups make an acknowledged or direct challenge to medicine, but their very existence may be challenging to it. Indeed the data from the current study suggests that cancer self help groups spend a reasonable portion of their time developing relationships with professionals to allow them to function in a way that is acceptable to them.

There is also a profound difference for a self help group that focuses primarily on prevention and positive health care. People who are coming together to help themselves and each other cope with an illness are less in a position to challenge medicine, or indeed society on a more general level. It may be unrealistic and unfair to expect them to do so. However the question of whether or not they challenge medicine is one influence on their contact with professionals.

SELF HELP : RELATIONSHIP WITH PROFESSIONALS

One of the greatest areas of interest in self care and self help is the relationship and interaction with professionals. Many professionals do not share self helps' social emphasis on health. The issue of the professionalisation of medicine had been dealt with elsewhere (Freidson 1970) with its effect of de-skilling people and mystifying common knowledge and practice.

This section looks briefly at the literature that presents a feminist analysis of professional health care provision, and relates that to similar difficulties in self help. There are notable differences between the approach of feminist health groups and self help in general. The relation of self help groups to professionals and their perceived challenge to formal services is viewed as it is presented in the literature. The difficulties for both professionals and groups are outlined.

From the feminist perspective there has been some attempt to try to address the dichotomy of patient/professional; ignorant/knowledgeable (female/male) not only in theory but in practise. Women have attempted to take care of themselves, and in some instances have tried to get special recognition for women and achieve access to health information eg Well Women Clinics (Foster 1990). They have also attempted to shift attitudes about the delivery of health care, and in some instances taken over that care themselves.

A feminist analysis by Foster (1990) suggests that the changes have been very limited. The relationship of the individual to the doctor seems to be distorted by the values and attitudes of that predominantly male profession. She cites evidence where women are diagnosed more on assumptions about female 'nature' than on the basis of scientific evidence, while they are offered advice that emphasises a particular perception of 'women's roles'. It is suggested that treatment is not concerned with the individual woman, but with benefiting and maintaining the

(patriarchal) society. Women themselves seem to feel that their treatment and health future may be compromised by any assertiveness on their part.

Zalewski's (1990) critique of this work points out clearly the dilemma that all feminist theorists and workers face; the solutions may be impractical or impossible at the time. These difficulties in relationships with professionals are highlighted primarily through a radical feminist analysis: they are structural difficulties that require a structural challenge. However, in reality these changes are difficult to bring about. Less fundamental moves may be possible producing some discernible and sustainable effect. The dilemma remains, as it did in the early 70's when women first took up these issues. The difficulties of an economically led health service continues to undermine any radical (structural) approach to health care. In addition, it is recognised that separatist clinics for women (one radical option) do not attract all women nor do they hit the source of the problem.

The women's clinics in the USA (Marieskind 1976) in many ways pre-date both the Well Women Clinics and the women's health shops initiatives (Scotsman 13/2/90). One focus has been to address the imbalance of relationships with professionals, and help people towards positive participation, giving information about illness and health in a non-patronising yet understandable way.

For many health self help groups these are also major issues. So what is their relationship to professionals? Is it as tentative as that of feminist groups - or are the self help groups judged according to their contribution or challenge to formal services?

Self help groups encourage members to ask questions of professionals, although they are well aware of the potential of being labelled. As Oakley (1984) points out in relation to her experience, it is a risk stepping outside that passive role that is allotted to you, and the danger is greater for women with an impending label of "neurotic" in easy reach. People, but women in particular, are placed in a dilemma about what is required of them, they are expected to participate in their own health care and take responsibility for their health, but also they must not overstep the boundary that expects them to be passive recipients of medical advice, in a situation where no credence is given to their own personal knowledge. This is summed up well by Mitchell (1984 pp167-8)

"In the last few years we have heard a lot about people taking more responsibility for their own health, Yet taking responsibility means learning about our bodies, not being passive, asking questions, and making decisions ourselves. We hear over and over again how some people will not take this responsibility. Yet how often do we leave the surgery with half a dozen unanswered questions in our heads? It is not just that the doctor's time is short. There is something about asking questions that does not quite meet with approval. we do not want to fall into the category of the 'difficult' patient. It feels dangerous to encroach upon clearly defined roles."

This is something that greatly concerns self help groups.

It is clear, that whether they like it or not, self help groups and professionals exist and have an influence in the same world. Perhaps the difficulties that these groups face in some way mirror the problems that women have in asserting their own health care. This may be a reflection of the imbalance of power inherent in the relationships. Bearing upon this is that the amount and quality of contact that groups have with professionals may not be as manageable as it is sometimes portrayed.

The relationship of a group to the formal services and to professionals is used by some writers as part of their definition of self help. For some writers in the field groups set up by professionals are not, strictly speaking, self help, while those that are largely autonomous qualify as self help.(eg Deneke 1982).

In the literature the question remains as to whether self help groups provide a forum for negotiation for better health care. Their ability to do so may rest, to some extent, on how they negotiate with professionals. A study of this (or these) relationships will clarify whether they do offer a new or different model for interaction, and how that is managed by both the group(s) and the professionals. This work attempts to contribute to knowledge in this area.

Kickbush (1981) suggests that self help groups may take up one of three positions in relation to professionals, they may exist within, next to or opposed to the professional services. This simple classification provides a framework for reviewing the literature. However surprisingly few published studies comment on, or refer to, relations with professionals. Where they do make reference it is unclear what position they take. The following analysis focuses mainly on health / cancer groups.

GROUPS 'NEXT TO' FORMAL SERVICES

Groups that exist 'next to' formal services are those which maintain their autonomy, but which may interact with those services.

Some groups do arise within the existing services, (eg. Bond 1979). Still more arise in some liaison with professionals, with Gottlieb (1982) suggesting that one in three self help groups were facilitated or prompted by professional workers. The sample of groups in this study is similar, insofar as two of the six were initiated and maintained with some professional input. The idea that self help has little contact with formal services does not hold up to scrutiny.

"Self-help groups are often erroneously believed to be anti-professional. The findings reported in this volume indicate not only that seasoned professionals have been involved in the founding and support of most self help groups but also that most participants utilise professional help to a greater extent than do non-members of self help groups, and in a number of cases (CR.,Naim and Mended

Hearts*) indicate a fairly high satisfaction in their experience with professionals.”
Leiberman and Boreman (1979 p432)

This is not the usual view that is forwarded of self help groups. That participants make use of professional services is confirmed by another study (Marques 1984). As Leiberman and Boreman (1979) suggest, the professionals who are involved in these self help initiatives are often those who are disenchanted with or critical of their own professional domain. They themselves do not adhere strictly to their profession, they have often moved beyond a narrow definition of their professional constraints.

Todres (1982) studied the attitude, awareness and use of self help groups in 308 professionals in Toronto. The professionals showed some familiarity with self help groups, made referrals to them and expressed favourable attitudes to them. Similarly Levy (1978) found that 48% of 748 professionals in psychiatric out patient clinics made referrals to self help groups.

A British survey of cancer self help groups was carried out by Alderson et al (1989) for Cancerlink - a self help organisation initiated by a professional who had cancer. They conducted a postal survey of 175 cancer self help groups, which indicated that the groups were 'grateful for professional support'. This support took a variety of forms (referrer, leader, patron etc.) and came from various professionals (nurse, hospital doctor, social worker, radiographer, Marie Curie nurse). The study articulates Cancerlink's policy of supporting peoples' trust in medical and nursing care, and thus defines its role in relation to services.

So it seems to be the case that professionals do know about and make use of self help, and that some self help groups are keen to work with professionals.

There are arguments, sometimes forwarded by the groups themselves, that formal services and self help groups deal with different aspects of health care, and perhaps both are necessary.

“Professionals are best able to handle problems requiring technical knowledge, expertise and objectivity, while the informal sector can respond to problems requiring long term adjustment and social support” Froiland et al (1981)

This may not be clear to those professionals who continue to be threatened by the mere existence of self help groups within their own area.

As early as Gussow and Tracys (1976) survey, it was stated that

“The quality of technical medical care is not the issue. Seldom in this survey was any criticism offered by group members of physicians or the quality of medical care they received.”

* Consciousness Raising (women's group), a widow's group and a group for sufferers of heart disease respectively.

Where self help groups are seen to 'fill gaps' in the formal service, it may not be clear that they offer something quite different from professionals. As Lindenfield and Adams (1984) indicate,

"Self help is certainly not an attempt either to usurp the role of the professional practitioner, nor to prove that he or she is superfluous...rather than self help being seen as some kind of Victorian substitute for statutory health and social services in a modern context which sees these as subject to massive cuts, self help ought to be seen as an enriching element, a partner alongside these statutory provisions."

Some would argue that deficits in services prompted the existence of self help groups in the first instance. This is generally portrayed as a deficit of delivery rather than of attitude. Only some indicate that groups recognise that they are able to do or offer something in a way that professionals cannot or do not. As Hatch and Kickbush (1983) indicate

"New social forms in health, such as self help, develop not only in relation to dissatisfaction with the medical system, but as a creative response inside the social system to problems that family and friendship networks do not and cannot provide for."

So self help does not remain merely reactive to the immediate situation, but provides something that moves beyond both formal and informal systems of care. Leiberman in Leiberman and Boreman (1979) suggests that people seek out self help and professionals for different reasons and with differing expectations. Professionals are approached in order to address a problem, self help groups in order to establish relationships with people. So self help can be seen as existing next to formal provision.

Where professionals do express an interest in more involvement with self help groups, this is often on their own terms, where they are fairly directive (Katz 1985). Some writers anticipate a future where self help groups would be the norm (in counselling) with the professional (psychologist) acting in a consultancy role.

In summary then, it appears that self help groups can arise within formal services, maintain contact with and have members who use formal services. Surveys in the USA suggest some professional knowledge of and referral to self help groups in the field of mental health. British work indicates that some cancer self help groups are willing to work with professionals. Questions about what the groups deal with raises issues about the political nature of the groups - potentially diverting attention from service deficits by attempting to fill the gaps in provision. There is some recognition that self help groups offer something unique, that may not be possible in a more formal set up. The contact with professionals is often on their (professional) terms and the difficulties of the role of professionals is not directly addressed. Some of these issues arise in the discussion of groups 'within' formal services. The views of self help groups on the involvement of professionals does not receive much attention in the literature.

GROUPS 'OPPOSED TO' FORMAL SERVICES

Alongside the view of self help groups existing independent of, but in some relation to formal service provision remains the view of self help groups as reactive, reactionary and even revolutionary. Knight and Hayes (1981) write (p1) that "The consultants made the extraordinary claim that the role of community groups was limited to 'protest and consultation'." Some groups undoubtedly do have political aspects to them, and some groups are specifically set up in that way. Levy (1976) suggests some self help groups get together to challenge society as a whole.

However, those groups that deal with health related issues, and those that deal with illness take up this revolutionary stand at their peril. Unless they are in a position to deal on their own with illness, they may have to be dependent (at least for technical expertise) on the professional services. This important distinction is seldom highlighted in the literature, that self help groups may critically challenge the delivery of service and the attitude of its practitioners without necessarily rejecting the expertise in that service. Health groups, of the type studied here are concerned with the social aspects of their illness, and with the attitudes that they come across in their treatment. They are less concerned with challenging the technical efficiency of professionals. This has never been made entirely clear in the literature.

Feminist women's health groups did challenge the technicalities of health care, but few other self help groups take this stance. Health groups tend to differentiate technical and social aspects of health care. Whether this is desirable is another question. Some would argue that in creating this dichotomy self help has encouraged a split in the delivery of health care, which relieves the 'technical' experts from attending to a human or caring role (Robinson and Henry 1977). The groups, perhaps unwittingly, no longer put forward an alternative view of health which is political/ social/ environmental, but one that is individualistic and thus focuses on individual coping.

On the whole, the literature does not suppose that groups which arise in 'opposition' to services necessarily challenge those services, but the wider society. There are difficulties, anyway, in any possible service challenge for those who are sick or ill. The bravery of the early women's groups has not been repeated. Indeed, it seems that many self help groups are not seen as challenging enough by some of the professionals who are involved with them.

The groups themselves seldom set out to be deliberately antagonistic to professionals. Some professionals may, however become opposed to them, perhaps because of misunderstanding of their aims and intentions..

GROUPS 'WITHIN' THE FORMAL SERVICES

Some groups are now so well accepted by professionals that they are in danger of being co-opted by them. Is it the case that self help groups can exist within the formal services, or are there dangers here? Gartner and Riessman (1977) suggest that "When the counter-

culture develops something of value, the establishment rips it off and sells it back." It is important to distinguish self help groups and volunteers within the formal services and professionals who use or encourage self help methods. Each is considered here.

Killilea (1976) suggests that self help might be an element in a planned service. She points out that as early as 1905 Pratt organised 'classes' for tuberculosis patients in Boston.

Tracy and Gussow (1978) see groups as positively attempting to modify the doctor - patient relationship, but being incorporated into the medical domain, with "the price of affiliation involving some degree of formalisation and some loss of autonomy". Similarly Dean (1986) points out the clear trend for professionals, mainly physicians, to encourage those self help groups which more directly interface with the (formal) system. Whether this is a welcome development or a dilution of self help, is a debatable point, and one that concerned group members and professionals in this study.

Some professional groups, notably counsellor and psychoanalysts (Moeller 1983) use self help groups for professional workers to alleviate stress and to provide support. It is a moot question as to whether these constitute self help under the definition offered earlier, where the group is set up by professionals, and professionally run, but those professionals also constitute the membership!

Some professionals do work with self help groups, seeing them as an adjunct to the formal services, usually as part of the support for chronic illness.

"Unquestionably, work with informal helping networks is economically advantageous in its ability to extend the reach of expensive professional services."
A.H.Collins (Consultant) in Froland et al (1981).

This assumes that there is a similar enough philosophy for the two to work together. It also makes assumptions about the cost of community care that has (in part) led the recent development of community based health care in Britain. Although Collins (above) is referring to general helping networks, there is a cost, to any of these helpers in the network. For members of a self help group in particular, the group activities do take a toll on their time, energy and resources, particularly of the more active members. This notion of self help as adjunct also ignores the different focus of groups; they may be concerned with issues that are outside the professional domain, ie of personal experience and social issues, prevention and self efficacy.

Professionals may liaise with self help groups, or use self help methods. Self help as a creative response to ill health and health care is seldom recognised.

"Professionals providing care in formal medical systems tend to view self care, mutual aid and services provided by alternative providers as inferior to their own. This tendency persists even when these forms of care prove to be more appropriate and effective than those provided by professionals." Dean (1986)

Killilea (1976) cites two examples of professionals working with groups. Stunkard (1975) with 'Take Off Pounds Sensibly' and (S.R.) Dean (1971) with a mental health group. Killilea sees the groups as "adjuncts" to the formal service with an appropriate "division of labour" agreed on. This co-operation was cited as a "solution to the shortage of professional personnel". The distinct roles of professional worker and self helper is thus unhelpfully blurred, in a way which benefits neither.

In the area of cancer care, there are some examples of 'self help' individuals working closely with professionals. Volunteer counsellors are particularly popular in the USA. The American Cancer Association lays down rules about who may or may not be a counsellor. These volunteers are only called in to talk to people at the discretion of the consultant. All volunteers are selected and trained beforehand, see Mantell et al (1976), Mantell (1983) and Markell (1971). It is arguable whether this does constitute self help, and at what level. There may be a danger here of 'mini-professionalism', where volunteers assume an almost professional role.

Kleiman et al's (1976) account of professionals and volunteers in CanCervive working together details issues that any group or professional who has tried this will recognise. They state clearly that collaboration of self help groups and professionals

"...can exact a price: self help groups must often surrender their autonomy and egalitarianism and curtail their sense of urgency in accomplishing their objectives; professionals find their identity, power and control questioned."

They conclude that self help groups "cannot find happiness within an agency". It is worthwhile noting where the power resides.

Weir et al (1984) in their account of Tac Tent, a Glasgow based group, aimed to help both cancer professionals and patients. Notable in their approach was the benefit to staff who expressed relief from psychological stress following feedback from relatives at the meetings.

"To be able to accept and receive support and reassurance from relatives or patients removes some of the pressures from staff who might otherwise...be in danger of becoming psychological casualties themselves."

Few other studies mention benefits for professionals although Tracy and Gussow (1978) indicate an educational element for staff.

There seem to be difficulties in general with self help groups acting 'within' the formal services. Professionals appear to have a tendency to dominate them. Individuals are more acceptable, as they come in and operate under the direction of a professional. Professionals seem able to use some elements of self help in their own work, but this does not constitute self help as it exists in self help groups.

Whether a group exists in any one of these theoretical relations with formal services, the implication is that there is some relationship to work out or to maintain.

THE DIFFICULTIES FOR PROFESSIONALS

It is important to distinguish between the relation of groups to formal services and their relation to professionals. Although in practice the two may merge somewhat, it is clear that although some groups have a critical attitude towards the delivery of professional services this is less often seen in their relations with individual professionals.

Thus the difficulties of the role that professionals might play in relation to groups is one that relatively few professionals consider. Most will have little to do with self help groups, and if there is one in the area in which they work, they may never have any contact with them. It is not incumbent upon them to do so. As Mantell et al (1976) point out

"Historically social workers and other practitioners have made minimal use of autonomous self help groups aside from recognising their existence as a limited resource. This may reflect the resistance of professionals to possible role threats as well as their valid concern over the groups' lack of accountability."

They conclude that collaboration should be based on a "clear understanding of all concerned of both the limits of the volunteers' role and the responsibility of the professional to support and to supervise."

For professionals the most common role that they are advised to adopt is that of facilitator (see Stewart 1990). Some see a move towards self help as a 'natural outgrowth' of professional work in community mental health centres (Chutis 1983). The expanding role of professional consultation is seen by Jacobs and Goodman (1989) as an expected outgrowth of legitimisation of a self help model of care.

Most writers are concerned about the difference in the values and attitudes between professional workers and self help advocates. These have been touched upon earlier and focus around issues of responsibility and autonomy. Professional workers continue to assume that they know what is best for people. The consumer approach to health care requires a change in attitude. They are cautious about who takes the blame when it goes wrong, because of litigation. This may explain their wish to rein in some of these groups, and their cautions about them. Groups are essentially uncontrollable in that they can set up and act on their own. This may make them a challenge to professionals more than anything. In reality, how easy or possible it is for them to exist in isolation from professionals is a moot question. It will continue to be a threat as long as even one group exists outwith the professional/medical domain.

However professional fears of accountability remain. This makes their relationship with self help groups difficult, unless they can drop their professional stance to allow them to facilitate groups without interfering - a hard role for many. It seems that those professionals who do take an active interest in self help are already likely to have extended their own professional role.

Accountability is a recurrent issue raised by or on behalf of professionals. In a self help group individuals choose to go along to participate as and when and how they wish. A group, or any other intervention, within formal health care has to consider the liability for those who attend. In the formal domain there seems to be some difficulty in letting people act with individual responsibility. For paid care workers the question of liability and its effect must always arise. However this accountability is also shared by 'volunteers'. Perhaps the difference lies in what is being offered, and on what basis. Whereas the formal services offer technical expertise to the inexperienced patient, self help groups offer sharing and a chance for mutual benefit between individuals. In the former the professional has a liability, in the latter all participants are accountable to each other.

In her review of mutual aid groups, Stewart (1990) takes 11 studies on the links between professionals and groups which although they did not address issues of partnership and interdependence, nevertheless highlighted areas of concern for professionals. Lack of information about groups and uncertainty about professional and self help roles were mentioned. In addition concerns were expressed about professional time and the training and orientation of professional workers. A concern was raised that self help groups provided false information. There are difficulties in this review, particularly in terms of the inclusion of studies of groups defined as self help which were professionally led and into which people were randomly allocated - it highlights important concerns.

Although many of the studies suggest a role for professionals, particularly as facilitator or referrer, professional workers may not be able to interact with self help groups in a useful way. Robinson and Robinson (1979) suggested that professionals tended to direct and determine the activities of groups. Similarly Jertson (1975) had warned that when professionals organised self help groups they lost their spontaneity, and he suggested that professionals should facilitate, and then withdraw. The overall conclusion of the Kleiman et al (1976) group was that attempts at collaboration did not work! It seems that indirect, non-authoritarian and non-directive interaction that groups want with professionals is hard to find.

THE DIFFICULTIES FOR GROUPS

With the notable exception of Leiberman and Boreman (1979) few writers attempt to examine the function and purpose of the relations that self help groups may have with professionals. There is an assumption that the groups can, in some way, determine their relationship with professionals. From the studies reviewed so far it is clear that this is seldom, if ever, the case.

Self help groups, like women, come from a position of relative powerlessness. They may be dependent for their continued existence on establishing reasonable relations with local professionals. They may have to do things to appease or reassure professionals about the

group. This is a crucial issue, particularly for health self help groups, and it has not yet substantially appeared in the literature.

More positively, although groups may feel they have something to offer professionals, this is seldom highlighted. Mantell (1983) offers a fairly aggressive and professionally dominated view of the usefulness of self help in their relationship to professionals, but she does, at least, conclude that "self help is worthwhile".

So although self help groups are sometimes defined according to their relations to professionals, there has been remarkably little work in this area, particularly in Britain. Many professionals seem to be keen on using self help methods, both for themselves and their patients. Professionals appear to see self help methods as an acceptable way of working, so long as it is under professional control. It may be popular as a supposed cheap option.

Self help groups share similar ground to the women's movement when relating to professionals, both as individuals and as organisations. The deficits in service and attitudes in some ways prompted self help, and partly prompted women's attempts to address the difficulties they experienced in health care. However many writers seem to have lost sight of the power imbalance when they discuss how self help groups relate to professionals. The literature does not ask what is the power of self help groups to determine their relationships with professionals. Similarly there is a lack of clarity about the challenge groups offer to the delivery of service, which is not necessarily a challenge to expertise.

Some professionals have raised the issue of accountability, as if self help groups, being unpaid were not accountable. This study suggests that groups hold themselves strongly to account, but they do not take responsibility away from the individual, rather they attempt to enhance the ability of the individual to take responsibility.

Therefore the questions remain as to what stance self help groups take in relation to professionals, and how they manage to function, given that they have to take some stance. The question of how groups attempt to maintain themselves and to work, or not work with professionals has received scant attention. There is little research material on the relative power positions of each and how these are managed. In particular there have been no British studies which take a detailed look at self help in a specific health/illness area and examine how the groups there manage their relationships with professionals. Similarly, there are no studies which examine the roles and perceptions of the professionals that the groups come in contact with. Whether they see groups as filling in a service gap, or undermining their expertise. This study attempts to address these deficits.

SELF HELP PROFESSIONALS

There have recently been moves towards providing clearing houses for self help groups in Europe. Coupled with this is a commitment to use professionals in the advancement

of self help. There is a danger in that the self help advocates, working from their professional self help roles, are unwittingly undermining the basis of self help in the community.

As Robinson and Henry (1977) indicate (p139)

“Even those who are very sympathetic to self help, as they understand it, tend unthinkingly to operate from a position that is dramatically opposed to one that would foster or encourage the political development of self help.”

Until the advent of the self help professionals the difficulties between groups and professionals were confronted on a local and personal basis. Now there appears in the literature the first grumbling of professionals already working in the community with self help groups and often using self help principles in their professional practice, who have difficulties, not with the groups, but with the professionals in the national organisations whose overall effect is to diminish the understanding between the groups and local professionals.

“There is however another professional on the self help horizon; people who are employed specifically to advise self help groups on resources and funding. Some of these consultants display the greatest resistance towards other professional involvement, and they succeed in engineering a hostile climate towards most outsiders...It is often in the localities where such individuals work that the greatest rift between the voluntary and statutory sectors exist.”(Lauder-North & Duddy 1985 p8)

Although this claim is not clearly substantiated, it remains a criticism of the effort to negotiate on behalf of self help groups. Whether this is due to personality or policy is difficult to ascertain. The literature that is available about the working of the self help professionals indicates their success in supporting self help but also highlights the dilemmas faced when working with this population.

SELF HELP ORGANISATION

Recent developments in self help strategies in England have been outlined by Humble and Unell (1988). Briefly, self help in Nottingham gained a higher profile with the publicised establishment of a Self Help Team, funded by the local authority, whose remit included systematic monitoring and evaluation. The team ‘supported’ self help and in 1984 a Leicester team evolved, funded by the local authority.

In the same year, 1984, the Self Help Network met for the first time, comprising workers and researchers in self help and this continued to hold annual meetings. The, then, DHSS helped establish a central supportive and evaluative group, called Self Help Alliance, this was part of the general community orientation at that time. This oversaw the allocation of monies as well as aiming to create a favourable climate for self help in general. Its output included a survey in 1988 published in the bulletin “Self Help and Mutual Aid”.

A National Self Help and Support Centre was set up in 1986 as an independent initiative to administer the Self Help National Network, and maintain a promotional role. It was

funded by the Volunteer Centre and the National Council for Voluntary Organisations. This continues to the present date, with a quarterly bulletin but is currently funded by the Department of Health.

All these organisational provisions took place in England and Wales, with no policy movement or additional resources discernible in Scotland.

There were similar changes internationally- with conferences in central Europe on an annual basis since 1985, plus the evolution of a clearing house for collection and dissemination of information, back up services, helping new groups, training, working with professionals, the media etc. The role here is as "concerned friend" (Wilson 1982) which still recognised the role of personalities at local level and information alliances.

Following a WHO Meeting in Copenhagen and the Alma Ata declaration "Health for All in the year 2000", the regional Office for Europe organised workshops and established an Information Centre on Research into Self Help and Health in the European Region. This promoted and supported research, at all levels, and tried to facilitate exchange and change professional training. They also sought to move national government policies and facilitate self help locally and encourage consumer participation.

The information available from these various organisations reflects the difficulties of self help at a smaller local level. Thus the Self Help team remain concerned about their response to groups and the best enabling role for professionals. They also face the difficulty of protecting the groups (from themselves as well as outsiders) while ensuring their independence. These concerns are reflected in the European organisation, and at the local level.

Taking this development as a template for self help generally, it is clear that things are moving, that self help has a higher profile and that governments are making some cursory nod in that direction. However if this template does indeed reflect the workings of self help as a whole it does not provide a radical challenge to the system from which it emerged. The aim seems to be to retain individuality while integrating -again this does not indicate a political challenge to the status quo.

It is nowhere clearer that the policy and principles behind actions have to be stated to avoid misinterpretation. In the recent government declarations for community care one might see great opportunity for the development of self help. If it is to be seen as a cheap alternative for maintaining people in an unacceptable state than it should be rejected for the panacea that it is. However if it promotes a genuine move to help people to look after themselves and make better use of the services that are and will remain, available to them, then the providers of formal care services can look forward to some stimulating work.

SELF HELP: SOME EMPIRICAL WORK

Over the years a number of studies have been published about self help and self help groups. Toseland and Hacker (1982) estimated over half a million self help groups in the

USA. The difficulties of any survey work is emphasised in the often ephemeral nature of self help groups, and the problems of defining these groups and recording their existence. Traunstein and Steinman (1973) attempted to survey a New York state community, they found more self help organisations (110) than traditional health and welfare agencies(100).

There are several published studies of self help in USA. Many of these are concerned with a wide range of groups, and a large proportion of the groups are concerned with issues around mental health. There are far fewer which focus on health/illness and only a few are concerned with cancer. (See for example Knight et al (1980) who use postal questionnaires for a variety of health and social groups). With the exception of those studies that raise important issues for self help in general, the emphasis in this work will be on cancer groups. Similarly in Britain, although there seems to be more general information available about health groups, there are few published studies on cancer groups, this despite the emergence of two major groups in the last few years, namely Cancerlink and Tac Tent. Interestingly both were initiated by professional people, one of whom suffered cancer herself. Why there should be so few studies published, given the apparent general and increasing interest in self help is a little baffling. Although there are recognised methodological difficulties in researching self help, there is also a case for looking for new ways of doing and publishing research, as well as adapting older methods (Branckaerts 1983) and Branckaerts and Deneke (1983).

Studies in Britain amount to a mere handful. Levy 's (1982) survey included 154 organisations of all types of self help groups. He concluded that women went more often than men and that there was a predominance of 30-45 year olds. There is no evidence that these general statements still hold true. The value of taking directories of self help as a basis for any such exercise only emphasises the difficulty of the task, as many of the entries are redundant or inaccurate by the time of publication.

Richardson and Goodman (1983) surveyed four national self help groups in Britain. The groups had a social, not a health focus.. The authors concentrated less at demographic data than how groups worked and why they developed different patterns. They found that self help groups were not a single entity, some being highly active, others holding only occasional meetings. Most groups were dependent on their active members and some groups found it hard to mobilise participation amongst members. People came to the group at different staged of their problem and wanted to maintain different involvement with the group. They conclude that self help groups are a valuable resource that should not be overlooked in terms of their (almost) cost free contribution. They make very little comment on interaction with professionals.

Alderson et al (1989) carried out a postal survey of cancer groups, and give some information about types of groups, meetings, activities and interaction with professionals (see p. 32).

Knight and Hayes (1981) studied the development of self help and community initiatives in East London. They concluded that there was very little that constituted self help in that area. Lauder-North and Duddy (1985) provide a series of chapters written by different professionals and lay people about their self help experiences. Similarly descriptive accounts are offered by Weir, Dean and Calman (1984) of the self help organisation Tac Tent, arising from Calnan (1984) and the concern for quality of life.

Eardley and Brown (1985) gave a brief analysis of the telephone contacts in one year at Call, a cancer self help group. This indicated that most people were wanting more information as well as to talk to someone. Indeed a major difficulty for most callers was attempting to get information from professionals, and they wanted help in approaching professional workers.

Robinson and Henry (1977) included some cancer groups in their work. The study has been criticised for remaining too entrenched in the authors' previous work in Alcoholics Anonymous (Richardson and Goodman 1983).

Brown and Griffiths's (1986) account in the British Medical Journal focuses less on their experiences of being active members in a self help group than providing some basic information for the medical readers about self help groups.

These constitute the bulk of published studies focussing primarily on health self help groups. There is little detailed information about health self help groups in general or about cancer self help groups in particular. There may be a variety of reasons for this which relate to the nature of the groups and the nature of investigative research. It could also be the case that much of the work that is done is not available in publications. Whatever the reason, there remains a deficit in our knowledge about and understanding of this complex phenomena.

BREAST CANCER AND CANCER GROUPS

Statistics suggest that 1 in 14 women in Britain will experience breast cancer. It remains one of the most prominent killers of women, although, worryingly, lung cancer is rapidly gaining ground.

It is not surprising that researchers should look for the psychological factors that seem to influence breast disease, as well as the psychological effect of the diagnosis and treatment. It is not intended to survey all the literature pertaining to breast cancer. However, several sources will be considered to look at the importance of psychosocial factors. The support offered from the professional and self help spheres will then be considered.

There have been suggestions that there is a link between psychological and biological aspects of cancer (eg Pettingale 1985). Others have concentrated on the link between the impact of life events prior to the disease and its onset (Funch et al 1983, Jones et al 1984). Recent studies have looked at the link with psychological factors (Greer & Morris 1975, Greer & Watson 1987) both in predisposing the individual to the illness, as well as a factor in recovery

(Weisman & Worden 1975) and future morbidity or recurrence (Greer et al 1990, Pettingale et al 1981, Ramirez et al 1989). Lazarus (1982) made a connection between stress and women's coping mode. The area was reviewed by Watson (1983) and Morris (1983). A recent British Medical Journal editorial (Lovestone & Fahy 1991) concentrates on psychological factors and breast cancer, suggesting that it remains high on the medical agenda. Interestingly few of these writers pay much attention to environmental factors, and concentrate almost exclusively on the individual. Many of the earlier studies of psychological factors in cancer are contradictory and are flawed methodologically (Ramirez 1988). Social, environmental and economic factors are largely ignored, and none of the cited authors makes any connection with the role that women play in our society (Roberts 1985, personal communication). This has occurred throughout history, and it is possible to question the motives of some physicians, as accounted in Greer's historical introduction (Greer 1983).

As evidence appears to be accumulating on the importance of psychological factors attempts have been made at individual intervention (eg Tarrier and Maguire 1984). Behavioural interventions are reviewed as of varying success by Cunningsham (1988). Intervention studies were reviewed by Morris (1983). A King's fund consensus conference recommends including a psychiatrist in the district team (Kings Fund Forum 1986). This suggests that women respond quickly and well to fairly minimal intervention, although less than 2% of those attending the clinic were referred (Ramirez 1988).

However (political) social and environmental factors continue to be ignored, despite evidence of geographical incidence and mortality rate (eg Eyles and Woods 1984). Thus the questions of perhaps why women may suppress their anger, or why they adopt a passive mode post operative are not addressed. There is no questioning of procedure or adaptation of the processes of treatment. This work does not answer these questions either, but it gives some hints of the pressures on women that come from being 'patients' within a powerful male dominated (medical/social) system.

Difficulties with lead time and dating the onset of a cancerous growth have made the link with life events particularly difficult. Prospective studies have not clarified the issue (see Stolbach and Brandt 1988). However it seems fairly clear that women do experience a variety of difficulties following the diagnosis and treatment of breast cancer (Maguire et al 1978, Weisman & Worden 1986). It is worthwhile bearing in mind that not all women want or need psychological support (Worden & Weisman 1980)

GROUP SUPPORT

Professionals, recognising the social/support difficulties that some women experience, have tried to offer this through groups. Some groups are run by professionals along strong therapeutic lines (Yalom and Grieves 1977, Spiegel and Yalom 1978). Spiegel, Bloom and Yalom (1981) describe the actual study which shows interesting, positive results for the therapy group at 10 years (Spiegel et al 1989). The range of work continues to those wholly or largely

initiated and run by members (ie self help groups). Between these lie a variety of possibilities of professional intervention/ self help initiatives, some of which are reviewed by Cunningham (1988). A few include trained volunteers (eg Kleiman et al 1977).

Most of these studies are American, with very little British work available. Gottlieb (1982) reviews the studies of cancer groups in the USA that use self help principles. He indicated the lack of well designed or controlled studies. Of these Spiegel et al (1981) showed benefits for women with metastatic breast cancer in emotional and psychological adjustment at 1 year after diagnosis following weekly group sessions. Groups were led by a social worker, psychiatrist or a counsellor, and it was suggested that they helped by talking about anxieties, providing companionship, "detoxifying" death, enriching the planning of remaining days and helping others give meaning to their lives. These groups are reported (Spiegel et al (1989) to influence survival at 10 years (37 vs 19 months for treatment vs control groups), although the numbers are small (n= 62).

Although not strictly speaking self help, these groups generally used self help principles, and highlighted the individual vs group process towards coping. A previous study by Bloom et al (1978) had indicated higher anxiety, depression and confusion in similar group members at 1 week and 2 months post surgery compared to a control group. This highlights the essential timing of these interventions, and suggests that hospitals may not be the ideal venue. It will be noted that most of the self help group members who participated in the present study chose to do so at an apparently sensitive period 3-6 months post operative.

Others have attempted to fit support groups into existing services, both geographically and temporally, by offering support groups, professionally led, at check up clinics (Gustafson and Whitman 1978, Herzof 1978, Aiken 1982, Blake 1984). All report varying success, but no objective criteria was used. One group (Herzof 1978) developed a core group which continued to meet over three years on a regular basis. It seems to have displayed some of the characteristics of self help (ie dealt with everyday problems, emotional issues, information and self advocacy).

In Britain, although there has been a rapid increase in the number of self help groups dealing with cancer, and much work in both Manchester and London re psychosocial factors in cancer, there appear to be no comprehensive published studies of cancer self help groups. Despite the enduring success of the liaison between professionals and lay people in Tac Tent (a professionally initiated, Glasgow based group) only one short, descriptive paper has emerged (Calman & Welsh 1984). Brief details are offered of a short questionnaire but no details are available about the groups, their organisation, membership etc. (It appears that further work is underway in Glasgow along the lines of the controlled study of Spiegel et al (1981) cited earlier.)

Similarly, a brief report of the volunteer telephone line of the Manchester group - 'CALL' (Eardley and Brown 1985) has not been expanded upon. Two of the founding

members of that group highlighted the working of the group in a short paper in the BMJ (Brown and Griffiths 1986). They presented an interesting but fairly dry overview where a more personal view of self help might have been welcome.

The development of Cancerlink, initiated by a professional, has provided the opportunity for research and publications, but this organisation has concentrated on the grassroots of groups themselves and cancer care rather than academic/professional research work. This is to be applauded given limitations in funding and time, but the gap remains.

One of the few British works has been the Cancerlink survey by Alderson et al (1989). They looked at 274 cancer groups. Of these about half had been set up by professionals, with 22% hospital based. The published study gives a brief run down of the groups, but no attempt is made to define the criteria for self help, thus the inclusion of professionally run groups. Most groups had meetings, ran a help line, and offered one to one support as well as practical help and information. Some had a social element and a few organised and ran a drop-in centre. Interestingly, only 11% were involved in any campaigns, and most of those were concerned with the closure of services, and not service delivery or content.

Perhaps this lack of published studies in Britain exemplifies the pressure on self help groups to conform in order to get any publicity at all in the professional journals. Maybe the limited number of publications are due to suppression rather than an actual dearth of work. Or perhaps the process of legitimation that was proposed by Leiberman and Boreman (1979) using professionals in the group, has not worked its way through to published papers. It may be that this reflects the attitude of professionals to self help groups in medicine and to breast cancer in particular.

VOLUNTEER SUPPORT

In addition to the attempts to set up group support for those with cancer there is an apparently increasing use of individual volunteers to offer support. This may take the form of one to one meetings, or programs to visit people while they are still in hospital. Volunteers are generally people who have had cancer themselves, and who wish to help support others going through the experience. On the whole this is more common and more organised in the USA (through the American Cancer Association). Some groups in Britain also offer a similar support.

It is important, however, to note that this is usually done on a one to one basis with the volunteer being (formally or informally) screened by a professional. Most volunteers also receive training from professionals. Interestingly, it does not seem unusual for consultants in Britain to enlist a few of their 'own patients' who act as role models for current patients. There is no literature available, but this practise became clear during the course of this work. These volunteers may or may not be members of the local self help group. However the input was totally controlled by the professionals. In this way it differs from the autonomy claimed by self

help groups. It remains an interesting aspect of cancer care which throws some light on self help, and so the main studies in this area are briefly reviewed.

Gussow and Tracy (1976) gave an outline of the programs and services of self help groups that included "visitation" of hospital patients. They pointed out the difficulties in this, in particular the extensive training of volunteers, and its sporadic acceptance by physicians and hospital administrators.

There is a body of literature from Los Angeles on the development of CanCervive (Kleiman et al 1977, Mantell 1983)) which charts the use of training counsellors who have themselves experienced cancer. They addressed the issue of the effect of such work on the participants. Over-identification seemed to occur, with some counsellors lacking insight into their own feelings as well as not recognising guilt about their own relatively advantageous health status. Despite all this they did seem to benefit the people they saw. There was no attempt in this study to relate how often professional workers experienced similar difficulties and how that might affect their own work. This research addressed the issue of responsibility, concluding that this was one of the major divisions between the work of professionals and the self help groups.

Houts et al (1986) failed to replicate these results, finding that in a highly supportive oncology unit a trained sufferer/counsellor was no better than a professional. It should, however be noted that this study took place within a formal service, and therefore is not comparable to a self help initiative.

It is interesting to note the distinction that is being drawn between the activities of the self help group, that take part outwith the hospital setting, and focus on social/psychological issues, and the hospital visitors who seem to be moving towards a more medical model where responsibility of the 'patient' is diminished. Thus external controls (screening, training, doctors' consent etc) are introduced and accepted.

Similarly work by Pruyn and his team in the Netherlands conducted a fairly extensive study comparing people with cancer (Hodgkins disease, breast cancer) who had contact with a fellow patient and those who did not Pruyn et al (1984). These contacts did not take place in groups, and most, but not all, had contact with a trained volunteer. (Others, presumably, had made the contacts themselves.) The results suggest that social comparison plays a large part for people as well as access to information.

Their study (Pruyn et al 1985) of volunteers suggests that they see their primary role to help others, and secondly to fill a deficit. Interestingly they noted personal development and distraction, as two other features of their volunteering. In the same general study Vink et al (1984) suggest that half of those contacted felt better, with a quarter experiencing some reduction in anxiety whereas only 17% felt they knew more about the illness. This confirms the primarily supportive rather than educative role of the volunteers.

Puhaty (1977) gave a personal account of being a volunteer. There is an emphasis on staying within set boundaries, with pre-selected (by physician) volunteers as well as visits only at medical request.

Carolyn Faulder (1982) reporting on the work of Betty Westgate, the initiator of the Mastectomy Association in Britain,

"Sad to say, these imaginative schemes met with a great deal of scepticism and indeed obduracy from many doctors, some of whom still persist in refusing to recognise that mastectomy patients have a problem at all...Doctors seem to be particularly antagonistic to lay volunteers, suggesting that they will frighten the patients with their experiences, or interfere with their medical treatment by putting subversive ideas into their heads. This attitude is close to paranoia in certain hospitals where even the medically approved leaflets distributed by the Mastectomy Association are not allowed."

A closer look at the relations of groups with professionals is long overdue.

SUMMARY

In summary, this consideration of the literature suggests that no author has drawn together the links between the women's health movement and self help groups as a whole. The historical impetus behind each shares a discontent with a simply technological view of health care and a purely functional delivery of service without an examination of the attitudes behind it and a consideration of those who use it. Self help groups, along with the women's health movement, are concerned with social aspects of health care and with helping people to achieve an optimum health future. To this end they seem to have experienced similar difficulties in their relationships with professionals.

However, the two differ in their approach. The women's health movement overtly threatened the status quo, and even attempted to supplant aspects of health care delivery. Self help groups, by contrast, do not on the whole offer any overt challenge to the medical establishment, nor do they attempt to or claim to supplant any formal services. Despite this they come against opposition.

It is noted that the progression of medicine has not generally fostered a personal view of patients, but rather focussed on illness and disease as impersonal entities. This has resulted in an (over)emphasis on technology and efficiency at the expense of any consideration of personal patient experience. The predominant model has been medical/technical, and self help challenges this by its emphasis on the social /psychological or personal aspects of any health or illness experience. This may mean the self help groups and professionals hold such differing attitudes they inadvertently come into conflict. Certainly these predominant but divergent views will influence relationships.

Self help as a phenomenon, has not been adequately defined or characterised in the literature. This, it seems, is partly because of a lack of detailed information as well as an assumption about the simple nature of these groups. Although self help has been seen as a

social movement, it is still not clear how much of a political or social challenge it offers. This may be in part due to an inadequate understanding of the relation of self help groups to formal services and professionals. In particular the difficulties a health self help group may face in maintaining itself has not been adequately addressed in the literature.

There is little information available about self help groups' interactions with professionals. Where it does exist it is patchy or incomplete. There is also a tendency to blur the distinction between self help groups, volunteers working with professionals, and professionals who use group methods. What little work there is available suggests that professionals remain concerned about accountability and control, with facilitation and referral identified as possible input. There are indications that any liaison of professionals and self help may be fraught with difficulties for both, with self help groups in danger of losing spontaneity and being dominated by well meaning professionals. There is no systematically collected information that explores the relationship between specific professionals and related groups. In particular the power of groups to determine their relations with professionals is largely ignored. This in itself may be related to who does the research and why. It does also mean that no good working model of interaction is emerging and that each time the relationship is negotiated it starts from the assumption that groups want and need professional involvement regardless of their inability to influence it.

A brief resume of recent developments in Britain and Europe suggests there should be more political and financial support for self help. The major developments of self help professionals and clearing houses is outlined, along with the first rumbling of criticism.

British studies of self help groups remain scant. Although there is a vast literature on the psychological aspects of cancer diagnosis and treatment and some professional interventions are reviewed, there remains little information about cancer self help groups. Some studies are available of professionally organised groups or professionally controlled volunteers, but in Britain, as elsewhere, there remain few studies of cancer self help groups.

This work aims to address this void and provide a detailed account of six cancer 'self help' groups, the experience of their members, their group experience and their interactions with professionals over a period of time. It will be noted that no previous study has attempted to look at several groups dealing with the same health area. Most studies have included a variety of groups interested in differing areas. It is only through a study of this sort that the personal aspects of the diagnosis and treatment of cancer can be investigated, and in particular the reasons why people seek out self help groups as a means of support.

The issues surrounding relations with professions will be examined in detail to help clarify this area both from the point of view of the groups and the professionals involved. No other study has combined the two for a comprehensive account of this crucial relationship. This remains a major focus of this study, and is placed within the context of information about people's experiences within the health care system and within the groups.

CHAPTER 2 : RESEARCH DESIGN AND METHODOLOGY

INTRODUCTION

Very little is known about self help in Britain. Any research in this area, therefore, must take this lack of knowledge into account and the methodological approach must also be guided by it. The information that is available seems not only incomplete, but there is reason to doubt its accuracy. Even briefly scanning the literature suggests that the important dimensions of self help groups are not known. Thus the people who do or do not attend, the reasons why they go and remain in the group, the relationship groups have with professionals etc. are poorly understood and under-researched areas. A survey of self help groups would be inappropriate given that the focal areas of interest have not been adequately identified. Indeed a survey approach might perpetuate the inadequacies already identified in the literature. Self help groups are seen as ephemeral, with changing locations, emphasis and populations which makes a survey method less appropriate. In this work a qualitative approach was indicated in order to provide in depth information about self help groups as they exist and as their participants and related professionals experience them as well as a means of refining the ways in which they are conceptualised. The study aims to be exploratory rather than evaluative.

As a research thesis is necessarily a small scale work the study of a small number of groups using a variety of methods was used to achieve an in depth analysis.

AIM

The proposition that people's experiences of health care should influence the health care system was part of a feminist argument, and is now adopted more readily by policy makers (see the Citizen's Charter (1991) and the Patient's Charter (1991)). Community initiatives are being advanced as a major new emphasis in health care, and professional involvement with these developments are important. Self help, in and of itself, constitutes a developing field of interest, and potentially a way in which people could have "more say" in the provision of health care. Self help groups are a single forum that encompass these three areas of participation in health care, the professional response to that and self help as a phenomenon.

The main aim of this work was to attempt an in depth study of six cancer self help groups, to document the personal experiences of participants of both health care and group participation and to explore the relations between these groups and professionals.

This was seen to be best completed by looking at members' personal experiences of joining and remaining in a self help group. This was to include an examination of the antecedents to joining a group in order to provide the context for contact with a group, the experiences of being in a group and the range of participation.

The group organisation was to be studied in order to provide information about groups' operation and structures. As many of the typologies of self help groups rely on an

understanding of their problem orientation, their activities and their structures these were to be examined in some detail.

A further aim of this work was to provide an examination of the interaction between self help groups and professionals. This was to be placed in the context of people's general experiences with health care professionals. This was to include not only the contact between the two but the use made of this contact by the groups, and the influences of each on the other. Although there has been some work in the area of professional relations with self help groups (Kleiman et al 1976, Mantell 1983, Todres 1982) no study to date has looked at these relationships in any detail.

This work did not set out to take a systematic sample of women suffering from breast cancer in order to find out why they did, or did not, seek out a self help group as a means of support. Nor does it attempt to evaluate self help groups and so contains no outcome measures. The former would have required a large sample, in order to identify a small number of group attenders, and, as women attend groups at various times after the diagnosis, the definition of the initial population would have been so loose as to be impractical. The possibility of using validated scales of psychological functioning and attempting a clinical assessment of group efficacy was considered and rejected as inappropriate given the limited understanding of self help. Other areas were considered more worthy of attention at that particular stage in the knowledge of self help groups. Similarly the concern with the way the groups operated did not include any large scale detailed analysis of group dynamics. Although this may have been of interest, it was outwith the resources that were available for this study.

The main research questions using this ethnomethodological investigation of self help groups and their relations with professionals were:-

1. How accurate is the picture of self help groups that is currently available in the literature in the light of the information in this study?
2. How useful or applicable are the definitions of self help groups available in the literature?
3. Do the current typologies adequately characterise and differentiate these groups?
4. Are relations with professionals an important dimension of self help group functioning, and how does this work in practice?
5. Are there any aspects of the self help group / professional relationship that are useful in informing policy?

Subsumed within these overall questions are others about the general functioning of these groups, what were the experiences that led people into them, and what were their expectations and understanding of groups. It is also important to look at the experiences of group members to see if groups are problem focussed, if there is a commonality of experience and how this is used in the group, and if the group does follow a self help model where helper and helped roles are interacted. The benefits and drawbacks for members is crucial in any analysis of group functioning that might throw light on group definitions and typologies.

In looking at the group / professional relationship, the contact between the two, how it takes place and by whom it is moderated is essential. It is important to see whether the groups appear to work alongside professionals, in opposition to them, or are included within formal services, and also what the benefits and difficulties of these relationships are. How professionals characterise their interactions with self help groups is also seen as an important aspect of this relationship.

APPROACH

Given that so little was actually known about self help groups in Britain, and very little of that related to cancer or indeed health, the most appropriate method of study was considered to be an ethnographic approach. This broad approach allows for an open ended exploration of responses and experiences without pre-determination or pre-aligned analytical categories. It allows the significant analytical dimensions to be identified through data collection and analysis, and thus to stimulate the development of relevant theory. The aim was not to provide an account of the objective states or an independent measure of morbidity or well being, but to look at the personal experience of being in a cancer self help group. In order to find out what drew people to engage in self help, and what maintained them in a group it was necessary to talk to them. Not only was it necessary to talk about the group, but also what led them into the group, and to do so from an informed position. As so little was known about what actually went on in group meetings some observation was required there. The information that was available about professional interactions with cancer self help groups came from the professionals working in the groups, and not through any independent research. Again, the personal experiences of the professionals in their contacts with the groups was sought, as well as their opinions and views about self help in general.

Taking account of the warning of Hatch and Kickbush (1983)

"In spite of the emphasis on the autonomy of self help groups, especially with regard to their goals, researchers may still approach with preconceived ideas of the particular tasks of self-help groups."

The guiding principle in the study was to accept from the onset that people's view of the world was a real and valid view. An attempt was made to utilise a meaning centred or ethnographic approach which places value on the personal point of view, and to integrate that with grounded theory (Glaser and Strauss 1967) which seeks to generate theory from empirical data. Qualitative data was sought, not as a preliminary to something bigger and greater, but for its own sake in the belief that its analysis constituted an end in itself. As Glaser and Strauss (1967) comment,

"qualitative research is often the most 'adequate' and 'efficient' way to obtain the type of information required and to contend with the difficulties of an empirical situation."

In a discussion on the methods that are available and appropriate to the study of self help Branckaerts (1983) comments that

“the aim (of research into self help) is constrained, not by the phenomenon being studied, but by the resources available to the researcher and by the goals of those sponsoring the research.”

The concern was, therefore, to maximise the benefits of the resources available to the researcher. In this instance the study was funded by ESRC, and linked with a government funded breast screening trial. Beyond requiring assurance that the work fulfilled the criteria of academic research, no discernible constraints were placed on the mode of enquiry or its expected outcome. This was a privileged position indeed, and avoided much of the difficulties that Branckaerts (*ibid*) encountered in his own research.

The aims of the study remained acceptable to the funding body as an examination of the personal experiences of group members, with an interest in group processes and interactions with professionals. Thus an ethnographic approach was adopted to make available the richness of experiences of women. This is not to say that taking the ‘personal’ approach to self help was done in an unstructured way, but rather that a variety of methods, all acceptable to the philosophy of the groups being studied, and acceptable in the wider field of research method, were used. Within the broad ethnographic paradigm such an approach to data collection is not unusual in the social sciences. Data triangulation, as it is sometimes called (Millar and Wilson 1983) is often used as a means of increasing the internal validity of a data source by ensuring a finding is not dependent only on the method or design of its collection. The richness of the data testifies to the methods used. There was little doubt that the academic link to the University was invaluable, as was the clinical link to the screening service, which further validated the research, in the eyes of some, being government sponsored.

Data were gathered from six cancer self help groups. In each group at least seven people were interviewed using a semi structured interview schedule. All in all 48 interviews were completed. A small selection (15) of the initial cohort were re-interviewed six months after first interview to provide follow up data on their activities etc within the group. Additional material was gathered in a less structured way in talking to people at group meetings.

For each group, attempts were made to attend at least one of each type of meeting. Participant observation of at least six of each of the groups’ regular meetings was carried out. Any group literature that existed was used to provide a comprehensive view of the group and its functioning.

A selection of professionals in contact with each group were also interviewed, using a semi-structured interview schedule. These were identified through their contacts with the groups. A total of 14 professionals were interviewed, and information was gained from others, eg speakers at meetings, in less formal conversations.

Thus the data collection methods consisted of participant observation of meetings, three sets of semi-structured interviews and documentary analysis of internal literature. Each of the main areas of groups, participants and professionals will now be dealt with in turn, to elucidate the data gathering process and the development of the research tools and the researcher.

GROUPS

The identification of groups* to take part in the study followed a simple and effective system where all the possible cancer self help groups in two large cities in Britain (Edinburgh and Manchester) were identified. As they amounted to a number that could be encompassed within the resources of the research, they were all approached to be included. The geographical basis of the study (Edinburgh) was unique in its service of comprehensive breast screening facilities to a selection of women following a clearly defined research protocol. This city also offered treatment of breast cancer in a specialist unit. Four self help groups were identified through contact with the nurse specialist in this unit. At this stage the initial concentration remained on breast cancer, but one of the groups identified had a focus on chronic pain. That group had been started by two women who had suffered cancer, and then focussed on the issue of pain as a consequence of the disease and its treatment. It included people who did not have cancer.

These four groups were not deemed sufficient in number for the purposes of the present research. There were no comparable established cancer self help groups in the rest of Scotland at that time and a further city (Manchester) was identified. This city was chosen as it compared essentially with the original location in terms of treatment facilities, although it did not have a research centre for breast screening. Its choice was then guided by a wish to study more groups and to examine if a research focus on breast cancer screening had a bearing on the relationship between professionals and self help groups. A formal comparative study of two cities was not intended. Contact had already been made there with professionals working in the field of breast cancer, and the city was well known to the researcher. The decision had practical benefits and would also ensure both practical and emotional support during the time of the fieldwork and interviews. Two self help groups were located, again an exhaustive trawl. These were included in order to extend the investigation, as well as to allow identification of any particular local influences on groups and their development. The latter yielded no significant data. It should be noted that the strict definition of breast cancer groups was blurred again at this point, to allow the inclusion of a growing general cancer group, that included women with breast cancer as well as women and men with other cancers and their relatives.

In inviting groups to participate in the study, the main aims were clearly stated and the need for certain academic and research standards. No group refused to participate. Indeed all

* see appendix (i) for description of groups

the groups were keen to be involved once rapport had been established. No doubt the academic and clinical connections mentioned earlier were helpful.

As indicated, the specialist nurse in the breast treatment unit was the first source of information in contacting the groups in Edinburgh. She had information about three groups, and was asked to mention the possibility of the study to each group. The researcher attended the next public meeting of one of the groups. Identifying herself as a postgraduate student at the university and explaining the idea (at the time) of a possible study of self help groups met with enthusiasm from the group. It also produced a flow of information about the other groups in the area, and other contacts in Scotland. The networking began immediately.

In Edinburgh each group was approached individually, through an identified 'key' member. This was facilitated by the nurse specialist with the first group. Once contact had been established with one group, the links between the groups ensured that the researcher was made known to the other groups. In this way, contact was facilitated with each group. So with group (A) following an introduction from the nurse specialist, the researcher attended a general group meeting. Two groups (B and C) were contacted by phoning a key member, and an invitation to a group meeting followed. With the fourth group (D), following telephone contact with a key member, a meeting was arranged with that member to talk through the study and access to group meetings and members.

In Manchester contact had been established with several professionals working in the area of psychosocial oncology. This led to introductions to two social workers and a specialist nurse involved in one group (E). Following this, a woman who attended another self help group enabled contact with that group (F). With group F, a meeting was initially arranged with the group leader before establishing attendance at meetings etc. There were no difficulties with establishing contact with the groups.

All the groups felt that they had a lower profile than they wished with local services. They saw the study as some sort of recognition of their work, and welcomed it. They were, on the whole, keen to hear an outsiders view of their group, and expressed few reservations about being studied. This may have been made easier by the descriptive and non-evaluative orientation of the work, as well as the inclusion of some group members in the development of the research interview. Areas of concern for the groups generally focussed around confidentiality, and a wish to protect group members from intrusion on personal issues. They were reassured on these points. Throughout the research period any data on a group (although not personal information) were open and available to the group. No-one took the option of access. In addition there was a stated commitment from the researcher to feed back the results of the study to each of the groups.

Related to the concerns mentioned, it was decided to approach the local ethical committee for advice and, if necessary, approval of the study. Their response indicated that no

formal approval was needed from them, as participation in the study was a matter for personal consideration of each individual invited to take part.

Throughout the study, one major concern was for the sensitivity of the women involved coupled with an emphasis on confidentiality. It was persistently emphasised that the study was a co-operative effort that would hopefully benefit both the group and the researcher. At every group meeting attended by the researcher care was taken to make it publicly known that she was there. This ensured that people did not feel they were being spied upon, and indeed facilitated the gathering of information as group members sought to inform the researcher of any new or interesting material. It would be fair to say that the groups accommodated the research very well.

None of the groups kept systematic records of group members or minutes of meetings. Where any such information existed, it was made available as appropriate. Most information about group functioning, and its initial set up and running was gained through interviews with group members.

As regards current functioning, participant observation of as many group meetings as was feasible within at least a six month period was carried out in each city. An attempt was made to identify all the different types of meetings, and to attend at least one of each. In practice, this meant evening and weekend meetings. Most groups had monthly meetings for all members, committee meetings, gatherings for new members, special purpose meetings etc. In one city a series of joint meetings for all the self help groups was arranged.

Although the possibility of non-participant observation was considered, it was assessed that the role of the researcher should assimilate towards the best possible integration within the group setting. As the groups aimed to facilitate communication and participation by members, to attempt to remain separate from that was difficult in that context. The group members themselves were much more at ease with someone who took part in what went on, as was seen by their reactions to some professionals who did not move out of their professional role within the group setting. Being participant within the group facilitated ease of communication, as well as gave a better sense of being a group member.

Participant observation seemed acceptable to all groups, although the degree of actual participation might be different in each group or at different types of meeting. It was deemed an appropriate method of study as it allowed cross reference for and validation of the interview material. The activities of the group and participants could be seen in context. It was also an essential element in facilitating interviews, as it provided the shared forum for discussion about the group and people's experiences within it. The participant observation also allowed modifications to be made to the interview schedule. For example, as it became clear that people under-reported their participation in the group, more specific questions on activity in the group were included.

The success of the participant observation method is revealed not only in the richness of the data that it generated but also by two incidents that are worth recounting. One group signalled their confidence in the researchers' ability to encapsulate their group by requesting that she represent them on a TV program when the member initially scheduled to do so fell ill. A second incident provides further, but more personal validation of the role of the researcher, but also highlights the difficulties of attempting participant methods where the basic criteria for complete participation (in this case the experience of treatment for breast cancer) is not met. During a heated discussion about surgery scars at a small group meeting, a relatively new participant pointed out, with some embarrassment, the fallacy of the statement of another member who had said "We've all got it - all of us here" by indicating my presence. A longer term member acknowledged the absolute truth of this, but qualified it with an indignant - "Well, but that's Shirley, she's one of us!"

Interestingly, in the same group, during a discussion where the researcher was pointedly questioning the group's approach to pressure group activity, one member turned and flatly announced "You don't know what it's like, you have never been through it". It was a woman who had been an active participant in the interchange previously recorded. Thus, although there was a clear acceptance of the presence of a researcher in the group setting, this never went so far as to blur entirely the distinctions in the groups. The participant observation could be said to have been as successful as it could possibly be, the researcher being entirely free to move within the groups, but never entirely outwith the research role.

Observations were sometimes noted during the meetings, if this was appropriate, eg during the speakers' delivery. These might include rough notes or key words of conversations, as well as more detailed accounts of happenings. These were then transcribed more fully as soon as possible afterwards. Much of these data related to discussion and chat with a variety of participants. In addition rough note was made of behaviour in the group, and particularly of the roles that people adopted.

PARTICIPANTS

Taking seriously the ethos underpinning self help and its development, it was essential to develop a method of investigating groups and their participants that met both the needs of the groups for autonomy, self efficacy and confidentiality as well as the needs of the research for investigation, good data and reasonable sampling.

In this field there has been an assumption that the aims of good research are somehow incompatible with good self help. Indeed some methodological stances would be highly incompatible with self help principles being both intrusive and controlling. However these issues are not new to researchers, and methods have been developed in feminist research which takes account of the person and their point of view (Oakley 1981, Stanley and Wise 1983).

One methodological hurdle was the identification of participants. As has been mentioned, few self help groups keep detailed and consistent records, if they keep any at all. Any possible comments about self help group participants cannot be generalised beyond the group to refer to the larger number of people who *might* be members. Even sampling within a group is thwarted by the lack of detailed or up to date information, as well as the dynamic and fluctuating membership. This lack of a sample frame has been recognised by others eg Levy (1976).

A further concern in identifying the membership of a self help group, is the difficulty in defining what constitutes a 'member'. For some groups this may be those who actively participate in group meetings, for others it may be all the people for whom they have records, which includes people who may never have attended any group meetings. This difficulty arises throughout the field of study of self help. Videka (1979) in a study of Mended Hearts (a self help group for heart surgery patients and their spouse) found the identification of participants problematic even though the organisation kept note of their fee-paying members. On investigation the researchers found that 32% of 'participants' had not attended a group meeting in over a year.

In that study it was also recognised that members fell into two classifications of active visitors (in a hospital visitor program) and those who were not active. This was also noted by Richardson and Goodman (1983) in their investigation of national social self help groups.

In this study the group members were 'selected' on the basis of their observed participation in the group, with a view to talking to a variety of people with differing inputs to the group. However, it was necessary to interview most of the more active members for information about the working of the group. Less active members might be less traceable, and indeed proved more reluctant to be involved initially, believing that they did not have much to offer in the research. However, no-one who was approached for a contribution refused. Indeed the difficulty was that people felt left out if they were not interviewed. But it remains that people who might be identified as 'members' (ie who received group literature) but did not ever attend a meeting during the period of data collection were not approached because this was seen to breach the 'rules' of the group. This does constitute a possible loss of valuable data which might be remedied in future studies.

At least seven people from each group were interviewed, making an overall total of 48. Of these 15 were re-interviewed six months later.

PARTICIPANT INTERVIEW

The structure and form of the research interview was crucial to the study. To some extent the comments of Oakley (1981) mirror the concerns expressed about self help. She suggested that women interviewing women diminished the power imbalance of the interviewer and interviewee, although often class and the power of disclosure can never be breached. In

this particular study, which concentrates on the experiences of women with diagnosed breast cancer, the major area of difference was not to be breached, because the interviewer had not been through that experience. As already mentioned, this came up as an issue from time to time in the groups.

Despite the apparent imbalances of power every attempt was made to make this study a collaborative effort with the participants. Thus the semi-structured interviews were developed after a brief period of participant observation and following extensive exploratory talks with 4 women from 3 different groups. They highlighted areas of concern for them as both individuals and as group members. They also pointed to areas that their own group was interested in. In turn the researcher, put forward areas of interest and concern. Thus the interview areas were established in a way not unlike that of Knight et al (1980) who developed their postal questionnaire on the basis of the literature, group observations and exploratory interviews with group participants.

The main areas of research concern ie people's experience in coming to participate in a group, the group itself and interaction with professionals, were all areas that the group members were also interested in. During the first few exploratory interviews, the participants were asked to comment widely on their experiences and their own questions in these broad areas. In addition, both in the 'interviews' as well as in discussions they put forward what they thought other peoples' experiences had been and their own understanding of that. They were less likely to comment on people's personal experience of diagnosis and treatment, but talked about their own in some detail. This expanded that section of the interview schedule, and helped to provide the linking section between hospital and home experiences and the time that led up to contact with the group.

Each person's experience of contact with the group provided new possibilities in this area, and as each focussed on their actual first meeting, this assumed a significance that was not initially envisaged. People were keen to find out how to recruit new members and what others wanted out of the group, and some had already fed back their own experiences to the group as a whole. Questions about the extent of participation were modified. Many people tended to say that they did 'nothing' in the group, and had to be specifically prompted in this area, ie asked if they talked to others, shared their experiences of specific events, discussed issues, made tea, washed up etc. The tendency was to offer only the highest profile activities as secretary, or chair etc. and to persistently underestimate participation at the level of personal support.

The section of the interview on relations with professionals developed from general questions about contact to look more specifically at interactions with individuals, and identification of particular roles or activities. This then moved towards identifying different views of this and ideas of the best input from professionals, and how that might be managed. In addition it became clearer as each interview progressed and more information came from the

participant observation, that the groups made strong use of the contact with professionals to validate the group. This was incorporated into the interview schedule. Thus this section moved from specific information to policy related issues based on the information acquired from a variety of sources.

The interview thus developed (appendix iii) focussed on three main areas, the personal experiences of the women in their diagnosis and treatment, and their views of the group and their participation in it, including their views on professionals in the group. The questions were developed following several interview and review sessions with three members from three different groups. These acted as widely exploratory session which were refined and open to comment from the interviewees. The final format therefore emerged from several in depth interviews/discussions with group members. Many of the women gave heartfelt accounts of their health experiences, of which only a very small sample is used in this study- those deserve a thesis of their own. The latter section, for which there was equally abundant material, was the main focus of analysis. Neither section would have been possible without the other. The group allowed women to make sense of their experiences, and it was those experiences that had led women into the group. Thus the section which concentrates on the diagnosis and treatment of breast cancer as the women related it, helps to clarify not only how they came to make use of the group, but also the role of the group in their lives and health care. It also helps to establish the dimensions of their experiences that were most important for those women, and which led them into looking for that particular type of support.

Contrary to initial expectations, the women reported finding it easy to talk about their experiences and some even said they found it helpful to have the time to go through it as a whole. For some it was the first time this had happened. No-one made it known to me or within the group that the interview had not, on the whole been a positive experience. In one group the complaint was that not everyone had been interviewed!

There was surprisingly little difficulty in conducting the interviews, all of which were carried out in people's homes. This was facilitated by the shared experiences the researcher and interviewee had within the group. No-one was interviewed who had not already had some contact with the researcher in the group context. This further validated the cross fertilisation of combining participant observation and interviews. Even questioning members about the drawbacks of the groups was seen as an area potentially helpful to the groups. Talking about difficult treatment experiences seemed to be the hardest area to talk about. There was concern that women would find this painful, as indeed they did, but there was some confidence that sensitivity would prevail here, and also that women themselves could take that responsibility. This reflected, in some ways, the stance taken by self help groups about personal responsibility. Interestingly, talking directly about this area of diagnosis and treatment transgressed one of the main rules of the groups - ie its avoidance of public discussion of

“medical” issues. However, it was not seen as ‘dangerous’ ie by inviting frightening personal comparisons.

There was some compensation for initial fears that women were being stressed by the research when Berthe expressed a wish to be interviewed, despite severely failing health. She made an extremely valuable contribution, and made it known that it was a help to her in her last days to have that opportunity. She died less than a week later.

In each of the six groups at least seven group members were interviewed. Everybody had already met the interviewer at a group meeting. The interviews took place in people’s homes, and twice were attended by women’s partners. The interview was tape recorded if permission was granted. Unlike in the research of Knight et al (1980), the tape recorder was allowed by the groups and used extensively. Only one woman refused, and on two occasions it was judged inappropriate. Interestingly, although everyone seemed to speak freely during the interview, it was often once the recorder was switched off and we were having tea afterwards that some of the real gems were delivered. This was often a time when women related their personal accounts of the cause of cancer, and when they most readily admitted the strain on their family. Although, with their permission, some use was made of this material, much of it was lost to the study.

A point perhaps should be made at this stage about the effects of the interviews on the researcher. Dealing with some of the information that the women were giving was extremely difficult at times. The role of researcher precluded any intervention, and there were a couple of occasions when sources of further help were suggested. On the whole, as the women themselves had coped to some extent with their experiences through the group, they were able to express their feelings and had often reached some sense of resolution. In reading some of these accounts the reader may well find they become angry or upset on the interviewee’s behalf. This unearthing of sometimes deep injustice and hurt, where intervention is excluded, does constitute an extremely stressful situation for the interviewer. No formal help was available. This had to be dealt with, and at the time several friends and research colleagues in both locations, took the brunt of that.

However tribute must be paid to the women themselves who took it on to offer support. The interviews usually ended in some resolution when they were carried through to completion. In some sense when they were brought up to date, the beneficial role of the group in their lives and the group as a coping mechanism was clear. The principle of self efficacy meant that they had chosen to complete the interview which helped us all.

An attempt was made to re-interview a small sample of women out of each group approximately one year after first interview. This was primarily to look at changes in their experiences of the group during that time. At least two people from each group took part in this follow up, although many of the women spoke in a less structured way throughout the research period.

It is impossible to credit enough each of those who took part in this study. Some indeed did not live to see the results of their hard work.

PROFESSIONALS

As the review of the literature has revealed, there has been no work published to date that examines the on-going interaction of self help cancer groups with relevant professionals. The few studies that are available about the role of professionals either examine one group (eg Kleiman et al 1976) or consist of postal surveys to a wide variety of professionals (eg Todres 1982).

In this study some of the 14 professionals were identified through an examination of the records kept by the groups of speakers and helpful contacts. Others were mentioned by the group members in interviews and discussions. Thus "key" professionals were approached on the basis of their contact and importance to the groups. This usually included a number of people who had been 'speakers' at group meetings, as well as those professionals mentioned as patrons or supporters. Interestingly in each location, the most prominent medical professionals were thus identified. It never arose that a known consultant surgeon was missed from the groups' lists.

Most of these professionals were interviewed about their contact with and impressions of the groups and their views of possible future contact. Only one (a professor) did not respond personally, being shielded by two efficient secretaries and did not reply to written communication within the time period.

Although the interview schedule (see appendix iv) was developed without extensive consultation with the various professionals it was kept fairly open. It took up themes that had emerged in the interviews with group participants. It also took into account the issues raised by the literature review about accountability and difficulties for professionals in assessing their relations to groups. Thus it moved from specific questions about actual contact with and knowledge about the local groups and self help in general, to stimulating more general comments on attitude and beliefs about self help, and professionals potential role in them.

The development of the interview schedule was helped greatly by on-going contact with a variety of professionals who were working in the area of treatment for breast disease, and in the screening project. They commented freely on the areas that concerned them, and noted comments from colleagues. Thus several professionals helped to identify areas of interest for them which were incorporated in the interview schedule.

Most of the interviews took place at the work location, and with the exception of those with social workers, took less than an hour. Where professionals attended group meetings this opportunity to prompt them to air their views was seized. Some professionals maintained contact with the groups and they were generous in their time to the research, maintaining contact throughout the fieldwork period, and in some cases beyond. The range of

professionals contacted eventually consisted of radiologists, nurses, surgeons, clinical psychologist, specialist nurses, psychiatrist, social workers, student nurses and social workers, breast screening project workers, community worker and health visitor.

In the final analysis these professionals were characterised by the sort of contact they had with the groups, being identified as those who worked 'within' the group and those working 'outside' the group. The 'within' professionals were those who had contact with the groups and operated, at least part of the time, within the group framework. These were mainly social workers and nurses. The others might have contact with the groups, but at no time could be said to wholly work within the groups' philosophy and framework.

DATA ANALYSIS

A wealth of data were produced by the methods indicated above. Needless to say not all were used in this study, but an attempt was made to utilise the most pertinent information.

The data analysis followed the grounded theory approach developed by Glaser and Strauss (1967). Several of the taped interviews were fully transcribed and from these a developing series of categories emerged. Subsequent interviews were analysed in accordance with these inclusive categories which were also adapted accordingly. Thus each interview was screened according to the basic interview schedule and tape references noted for each section, with only immediately interesting quotes being recorded in full on index cards. An example of this initial screening onto the interview schedule is available in appendix (v).

During this initial screening a large chart was produced to facilitate the development and refinement of important categories (sample available in appendix vi). This included, eventually, all the interviews with group members and notations of the relevant quote and tape reference. Thus areas of major interest were covered and emergent areas revealed. This facilitated the notion of theory development and was not constrained by previously set hypotheses. This meant that with each interview it changed and developed until a point of satiation had been reached.

Using this chart as a basis, specific areas were looked at in more detail using the tape references and the transcribed quotes. From this further quotes were gathered onto index cards which were increasingly re-categorised as analysis progressed. Thus all cards were grouped into areas of interest and further scrutinised for emergent divisions or distinctions.

To take one example as illustration, all the participants reported how they had heard about the group, with the exception of those who had actually set up the group. The main details and location of this section of the interview were recorded on the interview schedule and on the reference chart. This moved from "how people heard about the group" to people hearing about the group through "...media, friends, professional.." The "media" section, for example, was then subdivided into radio, television, newspaper article/letter. This revealed that people

had heard about the group from a variety of sources eg the media, friends, a social worker etc. Scrutiny of the interview schedule and reference chart led to a re-examination of some interviews with all relevant quotes from this section of the interview recorded onto cards until a point of repetition was reached. This revealed that there were a finite number of sources of information about the groups, and that these did indeed differ from group to group. (This later was compared with how people then went about making contact with the group.) Once this reached a point of repetition it seemed that the divergence of the data had been exhausted. Thereafter tape references were noted with only unusual or particularly pertinent quotes recorded.

At the end of this process it was possible to look at the information from the point of any category (via the chart and the pile of quotes), from each group (from the chart and by rearranging the quotes), and for each individual (through the interview schedule).

Care was taken during the development of the data to ensure some random selection between and within groups. Thus in the analysis of any section, any one of the groups might be the first to be scrutinised. Within that group there was no set ordering of interview material, so that each individual set of data were as likely to be looked at first as any other. The analysis did proceed group by group in order to isolate any particular group effects.

The follow up interviews were essentially treated in the same way, but with reference back to the original interview data.

Any notes, or other written material taken at the time of the interviews were used to supplement the taped data.

Information from professionals was treated in a similar fashion, with interview data leading the emergence of theory and further analysis. Thus the basic principle of searching for emergent themes began with inclusive ordering which led to more discrete categorisation.

The participant observation notes included not only numbers of attenders, themes of meeting etc. but also attempted to encapsulate the flavour of the meetings. This information was used to supplement the interview data as well as broadening the understanding of each group. These data were not regarded as sufficient to provide a detailed analysis of the psychodynamics of each group, and were therefore treated as additional material only. The information gathered highlighted differences and similarities between groups.

A research diary was also kept, with dates, times etc of interviews and meetings. This also charted the development of ideas throughout the research period in relation to events. This was used mainly to supplement the methods chapter, but in a sense underlies the whole thesis.

SUMMARY

The work emerged as an investigative, descriptive study that looked at the experiences that women had in the diagnosis and treatment of breast cancer, and how they became involved



in and used self help groups. The workings of the group and participation in the group as a member was examined in some detail. The groups' interactions with professionals was examined in some detail. In addition relevant professionals were interviewed about their interactions with, and views of, self help groups.

The data that emerged were rich and revealing, and validate the method of study. However there were constraints that should be borne in mind.

As has been pointed out, only a small number of people visibly use self help groups, and no attempt was made to make any comparison of the study group with the general 'population' of women with treated or diagnosed breast cancer. And although these remain the primary focus of the work, it must always be considered that there are men in some of the groups, and that one of the groups dealt with all cancers, while another moved to deal with pain, however caused. The inclusion of the latter two enriched the study, and remain included for that reason.

Part of the methodological approach adopted here was the commitment to feed back to the groups the results and observations of the study. This was agreed upon at the beginning as part of the research. This was done mainly within the group context where the researcher presented some of the observations of that particular group in relation to the others in the study. By this means some of the groups were helped to look at other ways of doing things and discovered interesting information about themselves. Thus one group who were considering how to attract new members were particularly interested to hear how their current membership had evolved, and expressed surprise at the various routes people had found into the group. It prompted them to review their publicity about the group, and how they invited people into the group.

For the purposes of this thesis each main area is reported in turn, following a more or less biographical format. Thus the experiences of cancer diagnosis and treatment are followed by an account of how and why people join a group and what they do in it. This precedes an account of professional involvement and views which leads onto a consideration of policy issues.

A brief vignette of each group is provided in chapter 4, with further details in appendix (i). Also available in appendices (iii) and (iv) are examples of the interview schedules used for the group participants and the professionals. Included in appendix (vi) is an extract of a data analysis chart, and in appendix (vii) a sample of the notes taken during participant observation.

The numerous quotes in the text are referenced according to speaker, who can be identified in appendix (ii) which consists of a brief introduction to participants. Only information directly relevant to the study is given, and care has been taken to conceal the identity of those who contributed. Clearly there may be instances where personalities are

identifiable to the participants who may yet read this account. Should this occur the principles of confidentiality that pervaded the groups and the research are relied upon to circumvent any major difficulty. On occasion extracts from the field notes are used, and these are identified as such.

Where quotes from professionals are used the speaker is generally identified in the text or else after the citation as is deemed appropriate, again with a view to confidentiality.

CHAPTER 3 : EXPERIENCES

"About August in the year 1810, I began to be annoyed by a small pain in my breast, which went on augmenting from week to week, yet being heavy rather than acute, without causing me any unease with respect to consequences. Alas, 'what was the ignorance?' The most sympathetic of partners, however was more disturbed....He pressed me to see some surgeon; I revolted from the idea, & hoped, by care & warmth, to make all succour unnecessary. Thus passed some months..."

Then consulting a surgeon (physician) the diagnosis of cancer is made and surgery indicated.

"M. Ribe (doctor) *charged* me to cry! To withhold or restrain myself might have seriously bad consequences, he said....What terrible inferences were to be drawn! I desired, therefore, that M. d'A. (her husband) might be kept in ignorance of the day till the operation should be over.... I obtained with some difficulty a promise of 4 hours warning, which were essential to me for sundry regulations. From this time, I assumed the best spirits in my power *to meet the coming blow*; & to support my too sympathising partner. They would let me make no preparations; refusing to inform me what was necessary..."

...my room, without previous message, was entered by seven men in black...I was now awakened from my stupor - & by sort of indignation - why so many? and without leave? - But I could not utter a syllable. M. Dubois acted as commander in chief. Dr Larry kept out of sight; M. Dubois ordered a Bedstead into the middle of the room. Astonished I turned to M. Larry, who had promised me that an arm chair would suffice; but he hung his head and would not look at me. Two *old mattresses* M. Dubois then demanded, & an old sheet. I now began to tremble violently...

M. Dubois places me on the mattress, and spread a cambric handkerchief upon my face. It was transparent, however, & I saw, through it that the Bedstead was instantly surrounded by the 7 men and my nurse...

...This pause, at length was broken by Dr. Larry, who, in a voice solemn melancholy, said, 'qui me tiendra ce sein?' - No one answered; at least not verbally but this aroused me from my passive submissive state, for I feared they imagined the whole breast effected - feared it too justly, for again through the cambric, I saw the hand of M. Dubois held up, while his forefinger first described a straight line from top to bottom of the breast, secondly a cross, & thirdly a circle; intimating that the whole was to be taken off. Excited by this idea, I started up, threw off my veil, &, in answer to the demand 'Qui me tiendra ce sein?' cried 'C'est moi, Monsieur!'. I was heard attentively, but in utter silence, & M. Dubois replaced me as before, &, as before spread the veil over my face...

Hopeless, then, desperate, & self-given up, I closed once more my eyes, relinquishing all watching, all resistance, all interference, & sadly resolute to be wholly resigned."(cited in Porter and Porter 1988 pp107-9)

These excerpts from the Journals and Letters of Fanny Burney are quoted at length. They bear a disturbing resemblance to some aspects of the accounts by the women in this study of their 20th century experiences of the diagnosis and treatment of breast cancer. The reader is urged to refer back to these writings from time to time, while reading the following chapter.

This chapter looks at the experiences of people going through the diagnosis and treatment of cancer. It clarifies the context in which self help groups became part of their lives. Mainly it concentrates on the experiences of women who had breast cancer diagnosed and treated. It was these events which led people into self help groups where they tried to make sense of their own experiences in the light of information from others. Women have written about their own experiences, giving their own accounts that are personal (Rollin 1976), investigative (Kushner 1975), political (Lorde 1980), and both political and pictorial (Spence 1978). Many of these highlight the difficulties women had in maintaining good communication with professionals about what was happening with their own health care.

In this work an attempt is made to detail the stages that women go through in discovering symptoms, acting on that information, experiencing the medical process, and returning home subsequently. Most of the information comes from the individual interviews with group members although use is made of data from other sources (eg group meetings) where relevant.

People tended to dwell more on the visible social or public aspects of their experiences. They concentrated, for example, more on the diagnostic procedure rather than the pain of surgery. There may be several reasons for this but it was clear that they edited the information within the context of a study on self help. Thus they presented those aspects of their experiences that were relevant to the group, those aspects that could be improved on and changed, or over which they, through the group might exert some control. They saw their experiences as something of value in the interviews and were not merely venting their difficulties. They were not looking for help or resolution, indicating, on the whole, that something had been already achieved through the group.

Throughout the process of diagnosis and treatment people were frequently and notably uninformed about procedure, treatment options, psychological effects etc. Afterwards they remained in awe of professionals, and were not moved to be critical of them. The groups proved that it was possible to survive the traumatic experience of the diagnosis and treatment of cancer, and go on and live a useful and productive life. The groups also allowed people to make use of their experiences in helping others by mutual support without necessarily antagonising the medical profession, or indeed, in most instances, attempting to change the deficiencies in the system they had tolerated. The group perhaps also facilitated a different possible approach to interactions with professionals.

Although the groups attempted to develop means to support and inform women as they were going through diagnosis and treatment, this was controlled by medical personnel, primarily the consultants. Attempts to offer support to women at an early stage eg at diagnosis were, on the whole, not easily organised. This reinforces the role of the group as a support system that operated at its most effective (both temporally and geographically) outwith the medical domain, and outwith the most powerful professional influence.

Many people were functioning very well at the time of first presentation, and the sinister implications of a relatively minor change in appearance, often with no functional dimension, had a strong impact. Thereafter women learnt to mistrust their appearance, and their ability to assess their own health status. The effect of this sudden change may be more difficult for women who are screened, but these data do not allow definitive comment in this area, and awaits another study. Women also had to deal with the implications of a changed appearance brought about by the treatment of the disease.

FIRST INDICATIONS OF ILLNESS

Given the relative rapidity of the transition many people go through in apparent onset and diagnosis of cancer it is useful to look at the clinical features which women "discover" that lead them toward a diagnosis. For most women the first consultation is with their general practitioner (GP) who may or may not assess that a specialist referral is needed. This may be the point at which the possibility of cancer is mentioned.

It was quite remarkable the number of women who had 'accidentally' discovered a lump or other sign. Often these "signs" were seen as possible indications of other illness - or not an illness at all. At first these clinical features were seen as part of everyday changes that might happen in one's body - a sharp contrast to women's fears of every slight change subsequent to a cancer diagnosis.

"When I was first diagnosed - I wasn't ill. I wasn't ill at all. I'd just found these lumps on my groin.

I'd had them for a while...I didn't think of cancer, I thought of hernia." Lily

And another woman subsequently diagnosed as having ovarian cancer said she had

"...this feeling of fullness. And I was putting on a bit of weight on my tummy, but I thought - I was just getting fat and I didn't think that it was anything serious." Notes: Mary

So the body changes that accompany the onset of the illness are not necessarily dramatic in the first instance, although they later turned out to be so. As has been commented on by Zola ((1973), it was often how these signs changed or interfered with social circumstances that prompted them to seek medical advice

"Ah hid this lump in ma neck, and of course ah hid phoned ma doctor...en here wis another yin. There wis two lumps in ma neck be this time." Notes: Kay

Sometimes attempts were made to disguise the changes in the body - and only if this became impossible was it taken as serious (in this case by the GP as well as by the individual concerned). One particularly illustrative example concerned a woman who eventually had a radical mastectomy.

"It was actually a leak, a small discharge from the nipple. Ah noticed it on ma bra actually. There was nothing to see at the actual nipple. Ah put up with it for wee while..." Lynda

Then she consulted her GP who told her it was her "age" and nothing to worry about.

"It gradually began to happen oftener and oftener. And ma bra would be stained and ah wis eventually going out one night with the shop where I worked. Ah hid begun to wear dark clothes in case this stain came through.

And ah niver went back about it because he'd said this (it was her age) and it really was stupid of me.

And ah wis going out this night and ah had this stain on ma dress and ah really wis upset about it. Ah thought 'Oh dear, if this comes through!' or anything, y'know. So ah phoned the doctor that night before ah went out. And ah went the next day (to the surgery)." Lynda

She was immediately sent to a surgeon (the following day) and had a radical mastectomy within two weeks.

What was significant about this particular sequence of events was not only that the GP did not recognise the signs displayed - but also that Lynda went to the end of her tether to cope with it. She eventually had to reluctantly re-consult because of the difficulty in maintaining an image or appearance, not because of pain. Also she looks back and takes blame and the responsibility on herself "It really was stupid of me". This not only underlines the self critical comments many of the woman in the study made, but also the apparent inability to criticize the medics, who certainly "mismanaged" this "case". This woman allowed herself no reprimand against the GP, except to say that she never went back to him - but changed her doctor. She was someone who was unlikely to 'have more say' in the delivery of health care.

Pain is not characteristic of very early breast cancer and this seems to interact with other factors to emphasise the importance of changes in body appearance. This was compounded as this generation of women did not and do not on the whole regard their bodies as their own, to be looked at, examined and touched by themselves.

Many women reported the accidental finding of a lump or other sign of breast cancer as a part of a change in the pattern of their everyday life.

"I was going on holiday and I was trying my bathing suit on in front of the long mirror - to see how revolting I looked. And it was the first time I'd looked at myself naked; and my breast came up like a balloon...and the nipple disappeared."
Chris

She then "disregarded" it and went on holiday.

"I spent the whole two weeks where every hotel had a long mirror opposite the bath. So I'd get out with my back to the mirror." Chris

Remarkable that the outward appearance of Chris' breast should so drastically change and not be noticed before. She assured me that she had not noticed until that time, and that she hardly ever looked at her own body unclothed. Subsequent to the initial discovery she attempted to reduce her anxiety by denial, by 'not looking' and avoiding situations where images of herself might be reflected..

Similarly Liza, when asked if she had ever practised breast self examination replied,

"No. I found it when I was in the bath. I was having a leisurely bath as I did not have to visit my mother that day. Our wardrobe has mirror doors and I saw it (a lump) in there. I felt it and it was very hard and I was aware of it for the rest of that day." Liza

So these women were doing something that they did not normally do. Liza looking at herself because she was going on holiday and had to check her appearance in a new garment, and Chris because her duties to a dependent had been reduced enough to allow her a leisurely bath. That is to say that these activities were not a routine or normal part of health or self care.

These examples, which are not unique to the study, emphasise how little time women of this generation spend on themselves/their bodies. It does call into question the advisability of promoting a health education type of policy in breast self examination - it is unlikely to be easily acceptable to these women. Most of the women reported little or no positive regard for their bodies as a whole.

Although the majority of women interviewed had promptly sought advice through their GP, they were fairly reluctant to take up the doctors' time with something that might be regarded as 'trivial' or 'just my age'. They were not generally confident in seeking medical help. They were also hesitant about facing the changes that had occurred to them. Some reassured themselves with the published statistics that nine out of ten lumps were benign, although only a few of them had that information at that time. Most women were uncertain about the significance of the symptoms.

FIRST CONSULTATION WITH THE GENERAL PRACTITIONER

The process of interaction with professionals started, for most women, with the initial visit to the general practitioner. As suggested above there may be a delay in seeking the opinion of the GP by some women, others did not delay. Some women in this study did not consult their GP. These women had the initial signs detected at the breast screening clinic, or who went there themselves having discovered symptoms. A few women were diagnosed through the Well Woman Clinics. However for most women in this study their first professional contact was with a general practitioner.

A GP is not a specialist in the diagnosis of cancer, but some seemed to recognise the potential gravity of the symptoms immediately, while others did not. This might be the first time when cancer was mentioned, or a time when it was avoided. Few GP's would have been able to offer a diagnosis, or even to realistically assess the possibility of cancer. What they were able to do, was to discuss a referral, to indicate what further assessment might entail, and to actually make the referral on. Unfortunately some GPs missed this opportunity of informing people about possible procedure, and one even made a referral onto an 'oncology' department without even mentioning its association with cancer.

It is standard procedure for the GP to examine both breasts, but this was not something that most women knew. Many GPs did not explain their own examination procedure. Several women were surprised at the examination, never having had their breasts palpated before, and in many cases not being aware of or not practising self examination techniques. Often women reported that that no attempt was made to explain to them what was going on, and that the doctor was quite uncommunicative about the symptoms, the initial examination or the subsequent specialist referral.

One woman who had a mastectomy at the age of 72 related her experience of going to the doctor.

"(I said to the GP)...it's my breast.", "Get your clothes off then". So ah wis jist goin tae let him see the one, y'know. "No" he says, "Take them both, let me see them both. "and ah knew be his face. He gave the show away." Mrs Sears

So the trauma of the diagnosis is woven in with the feeling of being out of control, without knowledge, and being rendered helpless.

At this stage women had discovered a lump, or other sign that all was not quite normal. A few women in the study were diagnosed through the breast screening clinic, and had never themselves felt or seen anything wrong or amiss.

"I was picked up at the breast screening,y'know at S---- H---. I had been before and they thought that they had found something, but it turned out to be ehm..just a lump. So when they said I had another, well, I didn't think much of it, really." Annette

These women had no delay in the process of their diagnosis etc, whereas other women may have delayed in going to their GP, or else the GP may not have recognised the symptoms presented. It seemed that the rapidity of the process for screened women was a bit of a double edged sword, with little time to adjust to the sudden change in health status.

For women consulting through the primary care system, further delay may come from the referral route. On the whole, however, once the primary agency had acknowledged the potential gravity of the symptoms, things moved fairly quickly, with the emphasis remaining on technicalities, and little consideration of psychosocial effects.

"Well he did say he would ask someone else to see me, and that I would hear within a week or two. He never really told me what it was - although maybe he didn't know. They didn't seem too keen to talk about it at the hospital either, but then I know now that they can't really say anything, can they, till things come back from the lab? But (GP) never mentioned cancer, it was me. When I got home, and he hadn't given me any cream or anything, I began to wonder. So I phoned up Joan, she used to be a nurse, and asked her. She came over with a text book, and well, that was it. I was convinced there and then, so I wasn't as shocked as some people." Irma

Thus when women are not given adequate information from medical sources, they mobilise their community resources.

ASSESSMENT AND DIAGNOSTIC PROCEDURE

The next stage in the diagnostic procedure involves one or two hospital visits for assessment (staging) including biopsy for pathological examination. Staging might involve aspiration cytology, where, under local anaesthetic in an out-patient clinic, a small needle is used to extract cells from the lump. Local anaesthetic is required for needle biopsy where a core of tissue is removed. Incisional biopsy also requires local anaesthetic and hospital stay, as the whole or part of the lump is removed. Procedure is relatively standard and straightforward but many women were unduly mystified, being offered no adequate explanation. Professional workers, for whom the various procedures hold no mystery, did not seem to communicate this well to women.

Often the experience was de-personalizing in the extreme.

"Ah really, ah thought ah wis gonnae die. They covered me up y'know, and ah couldnae see the surgeon's face. And this nurse is standing here beside me. And this great big thing over me. and she wis holdin ma hand. And he just stuck the needle right in the nibble - and oh jessum -ah hid that poor girl's hand crushed. Really, ohhh. Ah wis vexed. It wis really wicked.

.. "Ah don't know who he wis talkin tae, whither it wis me, the nurse or who. Bit he says "Ah think ah might jist take the nipple off.

Ohhh, y'know. He sounded that cruel. So nobiddy answered, whither he wis talkin to me or no ah don't know, bit...well ma whole body wis shakin." Mrs Sears

So her body was segmented and the breast cancer was dealt with in complete isolation from the totality of the human being. This woman felt so de-personalized that she did not know who was being addressed by the surgeon (cruel, wicked). (When she did regain her feet Mrs Sears gave them a good talking to!)

Such accounts of the biopsy stage were not common. However, few women felt informed about the procedure, most were afraid to ask and very few of them felt that it could not be improved. For many women the lasting trauma lay in the results rather than the process of the biopsy, although the biopsy and diagnostic time was extremely difficult for them in terms of uncertainty about both process and outcome. The outcome is difficult to predict or change, but the process is fairly standard, and the information component of it could be changed.

On some occasions the biopsy was an extremely frightening experience, mainly because people did not know what was happening to them and they confused medical terms and procedure. Certainly it has been the case that women would undergo what they took to be a diagnostic procedure when in fact it was the diagnosis and treatment. (Not unlike Kirsty, in the next quote, when the two were mixed up).

"And I went in for the biopsy - and it was a very nasty experience because it was under local and I was told it would take a very short time - just opening up and nicking a bit of tissue. In fact they did a lumpectomy.

Then we got over that, went along having the stitches. And I remember a man, the surgeon, registrar I should think he was. They told, y'know I was told he was nicknamed the butcher (laughs). And he said 'Do you want the good news or the bad news?'" Celia

This woman had a reasonable expectation of what was going to happen to her. She had the right terminology (biopsy, nick etc.) which implies some knowledge of the procedure. However the expected procedure is changed, for whatever reason, without her full knowledge or consent. Although this might have been difficult to predict, it could have at least been aired as a possibility. As it was, she had to contend with the removal of the whole lump without a definitive diagnosis. Thus diagnostic procedure and treatment are merged in a way that is understandable and justifiable for the professionals, but not for the women experiencing it.

Most of the women in the study were at least two years, and some were 10-12 years, post-operative. Thus their experience is a reflection of policies followed some time ago and may not be a basis for inferring present policy - if that has evolved over time. Nevertheless there is a distinct routine followed and it seems that this is seldom explained to women. So that the distinction between the biopsy as an assessment and surgery as a treatment are confused. This causes a great deal of unnecessary stress.

Further confusion came where women were assessed through a frozen section. Under a general anaesthetic a small piece of tissue is removed and analysis takes place immediately. On the basis of that outcome a lumpectomy or more usually a mastectomy is performed. So the woman goes under the anaesthetic with no diagnosis, and may wake up with or without a breast. Frozen section was more common in Manchester than in Edinburgh, and the women who had experienced it often felt that it was justifiable as 'everything is done at once', or 'it's all over on one go, you don't have to sit around and wait for results'.

However, some women were not as well informed as they could have been about the diagnostic procedure and confused frozen section with tissue biopsy done under general anaesthetic. Understandably many women used the state of their body - the presence or absence of their breast - as an indication of their health/disease. (Which, unfortunately, is not always necessarily highly correlated at this stage.)

Some women were gravely disappointed when they had misunderstood the clinical procedure.

"I had the biopsy on the Friday morning and I came round and I still had two, and I was over the moon. It was just great." Kirsty

Unfortunately she rejoiced too soon and the results being positive she underwent a mastectomy a few days later. This generation of false hope could be avoided, if women were better informed of the procedures that they were going through.

It is not clear whether a two stage procedure has any advantages over a one stage intervention. On the one hand there was a suggestion that the time lapse gave women time to

adjust to the diagnosis, and to think about treatment possibilities. On the other many women felt that this was one of the most difficult times in the whole procedure, and this has been confirmed in some studies (Maguire 1976, Fallowfield et al 1987). What was evident was the difficulty of being uninformed about what was actually taking place, whether it was an assessment or actual treatment.

DIAGNOSIS

There is no doubt that imparting a diagnosis of a potentially terminal illness is very difficult both for the giver and receiver of that information. One might therefore expect that attention would be paid to the circumstances and the way in which this was done. Past research (McIntosh 1974) shows that people, uninformed of diagnosis of terminal illness, make their own judgements based on staff behaviour. Thus people interpret the way they are spoken to or not as an indicator that something is wrong. Other clues, eg, the way the doctor sits on the bed, are used by patients as a way of inferring their diagnosis.

Many of the women in this study were told in a human and compassionate way that they had cancer. They were given time to deal with the implications together with family and friends and with adequate information from professionals.

"When he (consultant) came to tell me I knew. He had already asked if (husband) would be in, and he came about the same time. He seemed very, ehmm, cautious, but then said the results showed some cancerous cells, and he thought it advisable to operate. They would not be able to tell how far it had spread until they operated, and that made me angry. I thought what have I been going through all these tests and such for - if they can't even tell now! Of course, it was because I was upset, although I thought I had prepared myself. When (consultant) left, I just burst into tears, but..that didn't last long. I had to think about a few things and I wanted to know if there was an alternative to surgery." Kathy

This exemplifies a reasonably good attempt to impart the diagnosis. The woman felt that she had been prepared a bit beforehand, although indirectly. The consultant took it on himself to impart the information and chose what he judged to be an appropriate setting.

Many others were not so fortunate. They were left confused as to the results of investigations for weeks afterwards, and were told with little apparent compassion, and in an entirely inappropriate setting.

"It was when they got the results, and I was lying in bed. They make you stay in bed, which seemed really stupid to me, because I felt fine. But there were five or six of us in the room, and we were all a bit uptight. He (registrar) came into the ward, and as I said there were only five others there, and the nurse pulled the curtains. 'I'm afraid we have to do a bigger job on you, Mrs. T, we're not sure how far its gone.' And then he left, or that's how it seemed. And the curtains were pulled back. Well, I felt sorry for all the other women, because you could see they didn't know what to do. I suppose they were sorry for me, but they must have been relieved it was not them." Carol

Carol is careful to point out that this was how it seemed to her, that it was her experience, and may have been different in detail. Nonetheless the factual aspects indicated no privacy, no allowance for feelings, and an apparent avoidance of the use of the word cancer. These elements were apparent in other accounts.

Some women mentioned how difficult the general hospital procedure was for them, when they felt that they were treated as entities rather than human beings. They found it difficult to let the staff know how they felt, and were not always treated with compassion.

"Ah felt all shaky (at diagnosis) and you imagine the worst of course. So, ah said would they (sister or staff nurse) gie me something to calm down and she said no, that an' what if it was an arm that wis coming off or a leg. And ah thought "Well, right enough" Mrs Norton.

Other women had been examined by medical students as well as the registrar, consultant etc. They often did not know they had the right to refuse, and they were not approached for informed consent. Some women who did know their rights said that they 'would not dream' of saying anything.

"You go there, and you get prodded around and you come away. As I say when I know, I knew and everybody knew there was something there - at least 1/2 of the people couldn't find it.

A houseman - who was a woman - came to the side of my bed and said could she feel it. She said is it sore?? and I said, well it wasn't when I came in this morning - but you're the 17th whose had a feel.

... and okay if it was going to help someone else. This was different from what other people had had." Wilma

So all she allowed herself was a mild expression of her irritation, which was underlined by the resurgence of fear that she felt when the Houseman (sic) could not detect the lump.

THE TREATMENT OF CHOICE?

Once the diagnosis was made then the next step was a decision about treatment. Many women were given no option, some were fairly well informed and made their own decision, others were told there was no option. Research has suggested that doctors underestimate the amount of information people want, and that women could be involved in treatment decisions ((King's Fund Forum 1986). However there are conflicting reports of how helpful it is, in terms of pre-operative anxiety (Ashcroft et al 1986). Morris and Royle (1988) suggest that if women and their partners are involved in the decision about treatment they are less anxious and depressed both pre and post operative. However the difference is not statistically significant six months later. It is notable that they indicate the importance of 'proper counselling'.

Some of the women in the study had been diagnosed several years ago when mastectomy was the preferred treatment, or the only treatment available. The publication of

Fisher et al's 1985 results showing similar survival and disease free interval at five years for women treated with either simple mastectomy or wide excision plus radiotherapy meant that surgeons were more likely to consider conservative treatments. Women who had been diagnosed more recently, therefore, might be offered mastectomy, lumpectomy or other conservation treatment. This was often a difficult decision for them, as it required that they view cancer as a possibly localised or systemic disease, and weigh up the uncertain possibility of localised and/or systemic treatment. Thus communication with an informed expert was essential. This section concentrates on women's experience of surgical treatment, not because other options are any easier for them, but because surgery was their most common experience.

Many women treated by full mastectomy felt they had received the best treatment for them. Invariably (as the women choosing mastectomy in Morris & Royle (1988)) they subscribed to a localized theory of cancer and seldom talked about it as a systemic disease. This was perfectly understandable in the light of their experience, and the emphasis on 'the lump'. This view is the most commonly presented public view of the disease. This is exemplified in the script of "And the cow jumped over the moon" (Franceschild 1990) where Mary is incredulous when Gladys is said to have bone metastasis in her leg, "From yer breast to yer leg, how's that?"

For women the trauma of the decision was to balance their health against the removal of their breast and in the light of what they know about current medical practise. At the time they may feel unable to think about it clearly, the time lapse is short, and few received anything resembling 'proper counselling'.

"I think I was in shock really, because you don't get over it that quick (the diagnosis). But...y'know. I used to lie there in the bath and and think "My god, that won't be there on Monday". Anyway..." Chris

It is impossible to convey the infinite sadness and despair with which these words were spoken.

It had been suggested (eg Renneker and Cutler 1952) that women's distress was associated with breast loss. More recent work by Fallowfield et al (1990) found this in only 12% of their sample. Most women's main concern was having cancer.

Many women were able to justify to themselves that they had had a mastectomy - even in the light of information that they received afterwards that there might have been an alternative treatment. Few knew or were told at the time that there might be any option to mastectomy.

"At the time he (the surgeon) said to me that I'd be better having it all out. I wasn't so keen, but he told me that if I were his wife that's what he would want. Well, that seemed good enough for me." Nancy

For many they pondered over their treatment retrospectively and surprisingly few railed against it.

"I've heard about this lumpectomy, and I think I would have been a candidate for that. And there again, I analysed all this afterwards thinking. The sort of person that I am, it was best to get rid of all the tissue that there was - because it was suspect tissue. If it was going to attack it at one stage, it was going to attack it again. And I think it was the best thing for me." Nina

So one has to be a "candidate" for lumpectomy - not everyone can have it (which is true, it has only been shown effective in relation to early breast cancer). It was the idea of cancer attacking her body and alienating a part of her body that convinced this woman that mastectomy was the best thing for her. There is some reassurance in cutting it all out.

When questioned as to why some women prefer to have mastectomy, one woman said

"Its because the drug therapy is so awful, and you feel as if they are cutting out a piece of diseased flesh. There is something that you can see on the surface and not something that is going on underneath." Vivienne

This calls into question whether or not given the diagnosis and the pervasiveness of the localized disease model over the apparent understanding of cancer as systemic, whether women would choose other forms of treatment. The medical profession have justified their mode of treatment - confusing the two issues to cover both a surgical practice of mutilation and an apparent inability to adequately control the disease. Indeed recent research (Fallowfield et al 1990) confirms this impression, that women are willing to go along with the medical experts in deciding treatment, and furthermore they are not as keen as might have been expected to have conservation treatment that preserves the breast as far as possible.

For many women the more that they were cutting away the better, and one woman who had bilateral surgery (based on a single tumour, a family history of disease and incidentally a large bust!) said,

"To be perfectly honest, I just wanted reassurance that it would be got rid of. They could have cut off my head for that matter." Bessie

Those women who had surgery were sometimes trying for reassurance,

"But Thursday morning, I got up and looked at myself, and thought "Oh well, that's it. It's gone." But the worst aspect of the whole thing was that you had to wait six days for the result of the tissue test to come back from C's. And they came back negative. So they said "It was there, but it's gone. It hasn't spread to the lymph glands, it hasn't spread to surrounding tissue; you're okay". Jeanette

This recollection is not unlike the sort of communication that McIntosh (1974) found in the cancer ward in Aberdeen. Professionals deal with the uncertainty in diagnosis and treatment with attempts to maintain hope.

Sad to say for this woman "it" had not been and gone, simple though that sounded. Jeanette had a recurrence in the lymph nodes less than two years later.

Women also talked about other treatments, chemotherapy, radiotherapy and hormone treatment. Their experiences here were similar to those with surgical treatments. They were

unfamiliar with procedure, and uncertain what the treatment involved. Many women were sick during a course of chemotherapy, and one or two abandoned treatment.

The data in this section cannot address the question of whether and how women might be given choices about treatment for breast cancer. Most of the women were able to justify the treatment they had had, even in the light of further information from other group members. Thus the groups did not unsettle women, but rather seemed to help them to think through their own experiences. The women had not been demanding throughout their own diagnosis and treatment, and remained passive and accepting of what had happened to them, seeing it in the best light possible.

THE OPTION OF NO TREATMENT

No women in the study had taken the option of no treatment in the first stage, although at later recurrence they might reject further intervention eg. chemotherapy. One group member, with a diagnosis of Hodgkins' disease (which usually responds well to treatment) decided he wanted no intervention. This was an option that professionals found very difficult to deal with, as did some of his co-members.

It was certainly the case that medical policy tended towards intervention except where a decision was reached to not operate if someone was too ill, or if life-threatening metastasis was apparent at distant sites. There could have been little justification for mastectomy in those circumstances. Other treatments eg radiotherapy were deemed more appropriate than surgery. There were also indications that the quality of life of some patients was considered to be better if they did not have to put up with distressing treatment during the terminal period.

Most people nowadays know someone who has had, has or has died of cancer, so it was not surprising that people become aware of this non-treatment by surgical methods as a statement re life expectancy. (This may also have been an issue in the presentation of choice in conservative treatment)..

"My main fear at that time was in fact that they might not remove it. I was very happy to have a mastectomy. My friend who died did not have a mastectomy, and that was because it was too far advanced...There was no-one more pleased to have a mastectomy than me. I was delighted to get rid of it." Annette

So there was an interaction between the image of the cancer and the changing image of the breast. The breast became a diseased part, alien flesh even to the woman herself. A similar terminology was present in conversations with medics, who use the metaphor of war to describe the disease, eg cancer attacking, the body defends itself, treatment is aggressive etc.

SUMMARY

This section has attempted to look at some of the experiences of diagnosis and treatment for cancer that people had that led them towards the group. Some people seemed to

have been well informed and helped through the diagnosis and treatment, however many had received little in the way of support. The most common experience was of lack of information about the illness and about hospital or medical procedure. The whole process seemed to be characterised by people's inability to participate actively in their own health care, often through lack of opportunity and information. Thus people, within a few weeks, moved from apparently healthy individuals with minimal signs of illness (and sometimes none at all) to cancer patients with a reduced life expectancy. It seems remarkable that so little attention is given to psychosocial issues by professionals, and it was self help groups who took up these issues.

During the process of diagnosis and treatment, people are also strongly influenced by popular images of cancer, in the lack of other information. It is on this basis that they approach the possibility of treatment options. There remains a confusion between cancer as a localised or systemic disease requiring appropriate treatment. Most women are able to justify to themselves the type of treatment that they themselves had, and were not moved to question the system they had been through in anything but a general way, and then usually on behalf of others.

At the end, they are left with both a different 'image' of themselves in terms of health and, often major changes in their body and body image. This seems worthwhile exploring in more detail, but remains outwith the current study. The following sections continue to trace the experiences of women through the impact of breast loss, changes in appearance and re-adjustment to life at home.

Up till this point the procedures that anyone went through would have been more or less similar. Different women would now receive different treatment(s) and some would be fitted with prosthesis, others offered reconstructive surgery. These will be dealt with in turn, as they were issues of concern to the groups, and the groups sometimes played a part for women in the decision of reconstructive surgery, or prosthesis choice. These issues straddle the time between home and hospital, but as they remain, to some extent, within the medical domain they will be dealt with first. Thereafter a short section on the reaction of male partners is included, and the chapter ends with a section on the difficulties women faced in going home, and coming to terms with a very different image of themselves, both in how they looked, and their health status.

THE FITTING AND WEARING OF BREAST PROSTHESIS

"A LUMP OF PLASTIC"

Research no longer supports the idea that women's distress following breast disease is related to breast loss per se, but they are more concerned about having cancer (Hall and Fallowfield 1989). Nevertheless, breast prosthesis and their fitting were of great concern to women as individuals and to the activities and philosophies of all the breast cancer groups. It became apparent that this was, for them, a "legitimate" area of concern - it was outside medical experience, peripheral in terms of medical control, and made fairly central to the expression of

well-being in the group. It was strongly felt that this was something that the women could take issue with, without directly confronting the medics or antagonizing them.

There is a generally agreed standard procedure followed in the fitting of an external prosthesis. Most hospitals had a surgical fitter, who should have (hopefully) a variety of types and makes of prosthesis. In reality often the fitter was an independent agent affiliated with one particular firm which designed and made breast prosthesis.

On the whole a women who had had breast surgery would be seen by a trained fitter, who showing her a variety of prosthesis, should measure her and advise her as to type etc. In optimum circumstances the opportunity was there to at least see, if not try several types and sizes of prosthesis, and choose on comfort and appearance. This fitting should also be done at a time when the effects of surgery have been reduced ie the stitches have healed and swelling has gone down.

In the interim period women were generally given a soft prosthesis made of light cotton to wear, to give them some shape, but which would not press against the wound.

In reality very few of the women in the sample went through anything like this procedure. There were some who had, and on the whole they were as satisfied as they could be. But generally there was a degree of discontent that surrounded both the actual process that had been experienced and the personal management of the process by the fitter, not to mention the actual prosthesis itself.

To begin at the beginning - On leaving hospital, most women were given a "comfy", a soft bra filler that they put into a bra. On a couple of occasions this did not happen and the woman was not given any sensible advice about a bra.

Women who expressed concern (to surgeons) about their appearance were sometimes reprimanded.

"The doctor, y'know the original doctor. I don't think he believed in anything like that reconstruction. He'd saved your life and as far as he was concerned it didn't matter how you looked. He'd saved your life and that that was all that mattered - and really you should be grateful.

I was quite upset, as I say, when I was coming out of the hospital I said to him Is there nothing I can wear? And he said - 'That's just sheer vanity' and stormed out of the room." Sonya

So Sonya was told that her life had been saved - so why calculate the cost. Certainly the only criteria this consultant seemed to have was of medical "success", no consideration, apparently, was given to quality of life or psychological well-being.

The effect of not being offered a comfy was profound,

"When I came out of hospital I didn't..now they have a comfy. I wasn't even given a comfy - and I felt so embarrassed. It was a warm summers day and I had a summers dress on, and, eh, I felt absolutely stupid. It's alright if you're a bit flat, but if you've got a bit of a bust, and you're sunk in here - oh, it was awful." Olive

and later Olive, like other private patients, had to not only buy her own prosthesis, at an average approximate cost of £60-70 (in 1966) but had to find them herself.

"I had to rely on adverts in the paper for prosthesis. Being private I didn't get one on the national health. I had to pay for them. And as I say, I was just issued with the one, one type of prosthesis. I wasn't shown any other. The fitter just said that she thought this one was best for me. Really I had no say in the matter. I thought that that was just normal. If you don't know any different than you just think that's normal procedure." Olive

Unfortunately although Olive's experience at having to subsequently find her own prosthesis is uncommon amongst NHS patients, her experience of the fitting was in no way unique.

Her explanation was one that pervaded much that was talked about in the group in terms of experiences ie. that women tend to regard their experience as the norm and only later realized that the procedure could be, and in some instances was, different. It seemed that they were so dis-figured anyway that unpleasant experiences during fitting were taken as normal.

Faced with the reality of the loss of a breast, these women had now to make a decision about a prosthesis. None of the women had ever seriously considered not wearing a prosthesis (see Andre Lorde's account 1980) although some of them would only wear it in public. So they all, with the exception of a few women who had immediate breast implants, went through 'a fitting' of sorts.

It is only fair to say that many women were excellently fitted, and that many changes were made in the process of prosthesis fitting in the local hospitals during the time of the study, perhaps as a result of the publicity in the groups. Some women were well received and regarded by fitters in their changed body state and the process was accomplished in a relatively sensitive and human way.

Often the fitter will not have a supply of different prosthesis, and they have to be ordered.

"Ah went along a few weeks after the surgery. Ah think it was ma GP who said to go...luckily someone decided that they didn't want the one that fitted me. And it was, oh.. ah got it on Christmas Eve and ah was delighted...because ah was able to go out. And ah thought ah must have something new to cheer me up - so ah bought ma self a nice sweater and skirt and a fancy scarf. Ah wasn't able to do much of course, but..." Mrs Farquar

For this woman, as well as for others the fitting of the prosthesis was something easily accomplished and which gave her a sense of freedom. She could present as normal to the world. She was no longer visibly a cancer patient.

For many women the prosthesis and its fitting was seen as another indicator of their illness. To some it brought the realization that their body/health had changed, and would remain

changed. Not only was the prosthesis itself a visible shock to many women, it was also a visible reminder.

"Well, that was a disaster. I was fitted the Friday following the operation. I still had the stitches in and only had the drains removed that morning. I can remember it well. I'd never before even seen a photograph of a prosthesis. The fitter came and showed me and it was horrible. and it kind of hit me what had happened.

They were not at all realistic. I, when I said this to her she replied "I can't help that, you'll just have to make do with it"

I had always worn a lightweight bra, and of course that was what I had with me - and that was no good." Liza.

Several points emerge from this account. Liza had now, like others, realised too late for herself, that she was fitted at an inappropriate time. She also was shocked at the sight of the prosthesis, which was something that she would have to contend with for the rest of her life. Finally, it was apparent that she had not been prepared for the fitting as no-one had mentioned to her that she needed a firm control full cup bra.

"But I was fitted up quite quickly. I was fitted up before I had the treatment which was in April. I didn't wear it for three months because you get marked. Y'know the blue, they mark you with could come off. So they said go back to your "comfy" one ... mine is perfectly alright really." Lynda

(The "treatment" referred to here is radiotherapy.)

Small changes in the information and understanding given to women could make the whole process less threatening and downright unpleasant. Policies could be adopted that considered these issues.

Liza (quoted above) did in fact use the little knowledge that she had, and her common sense scepticism, to attempt to control the situation. She continues her account,

"I said that I had heard of some with a nipple, and she said there was, but to take this one in the mean time and I could get the other later. But I wasn't going to do that. As they would not be so keen to give me another one if I already had one. she said that she might have some others downstairs and would look. Of course as soon as she went I went into the loo and burst into tears." Liza.

There was little doubt that the prosthesis and its fitting marked some point in the process of events for these women. There is little that can be done to change the look of prosthesis, and what can be done is taken on as a business venture by the manufacturers wishing to attract trade. Their appearance need not, however be exacerbated by insensitive fitting.

"I could keep you here for a fortnight talking about that...I was in a very bad way with that. I was at W.. hospital and this very peculiar lady appeared with a Tesco's trolley piled high with boxes of bits and pieces...She sort of looked at me. "Oh yes, you're size 10." She threw this revolting looking thing at me. It was horrible. It was as bad as trying to handle someone's false teeth, y'know. It was a horrible thing. I couldn't describe how I felt - it was revolting.

It was only a lump of plastic, but I couldn't touch it. I couldn't handle it, oh it was awful. It was a terrible looking thing.

...after I met M (the nurse counsellor in the group) she said she was appalled. I should have had a lump of cotton wool to come home with and not been fitted with my prosthesis till 3 or 4 weeks afterwards. But I mean nobody told me. So I accepted this wretched thing.

Also when we get down to the bottom line, the one that she had given me was size 10, and when we got me fitted properly I was on a size 6! So you can imagine what I was like." Chris

Chris' account incorporates all the elements of the worst possible fittings; done too soon, inaccurately 'fitted', no choice allowed, no explanation etc.

It certainly was also common for women not to be told how to put the prosthesis in their bra. One woman said that she had worn hers upside down for 2 years before she came to the self help group and found out different.

Sometimes women who have a very badly fitting prosthesis wore it for prolonged periods of time, even knowing it fitted badly and felt uncomfortable.

"Ah wis swollen up after the operation, and ah think NOW ah knew that this was wrong. But at that time Ah wis quite happy with it. ...Ah couldn't wear it for a long time because Ah wis going for the radium treatment...they told me not to wear it because it would irritate the skin.

When Ah did start to wear it, Ah thought it wasn't right. But Ah wore it, for years. Ah'm wearing it now actually." Deidre

For one reason or another few women wore the prosthesis all the time. Some started off not wearing it, and others chose to wear it when it suited them.

"I didn't wear it for four years. it wasn't till I started going to the meetings (of the group). It's eight years this month (since operation)...A lady came demonstrating bras. Oh and ah took a very sore arm. When that lady was explaining, when you don't wear the prosthesis ye can take a sore arm, because yer not balanced. So ah took two of her bras, and I've worn them ever since." Mrs Norton

So this woman decided to wear the prosthesis not for the way it looked but for reasons that she saw as related to her health, and because of information she got through the group.

Other women did not wear it because they just didn't like it much, or that it felt uncomfortable, even though expertly fitted with the best intentions.

"I'm a wee bit hollow there (under arm), so she fitted me with a prosthesis that comes round there. But I've got a fat arm. This arm is slightly fatter than that one since the operation. This one swelled a bit, and of course I'm left handed which makes it worse.

It looks better if I'm dressed and going anywhere, I put it on because I'm not going to be using my arm much." Lynda

So for public appearance one bears a degree of discomfort, but the overwhelming concern most of the time was for comfort, and personal well being.

Some women did try and find alternatives to the commercially produced prosthesis, sometimes with success.

"Ah wis given something that Ah didnae find very satisfactory and Ah've tried all different things. And Ah ended up going to Woolworths, and y'know if a person, anyone, had a small bust they can buy those things for going inside their brassiere. so that's the answer that Ah found." Geraldine

"I was fitted, but it was a sort of rubbery thing...I found it heavy." Kathy

"I just used to stick a piece of cotton wool in my bra." Mrs Norton

There were also tales of women who still wore bags filled with birdseed. During the study period no-one came forward who still did, although some women said that they had bags in the first instance.

Although after some time most women were able to find something to wear that was tolerable to them, there was little doubt that most women did not wear their prosthesis all the time. It was not unusual for a woman to take out her prosthesis to show it during the interview, and then not to bother putting it back in.

"They're not comfortable things to wear. We all sort of take them out and slip them down the chair and as M says there's an unholy rush to find it if the doorbell goes!" Mrs Farquar

BREAST RECONSTRUCTION

"AH NIVIR REALISED"

Theoretically there was an option for some women to have conservation treatment for breast cancer, determined primarily by clinical considerations. It is not proposed to enter into the argument from a clinical standpoint but rather to look at how the women who had this type of treatment or who later had reconstruction or implant viewed their treatment and also to examine how it was "offered" to them.

As radiotherapy had become more viable as a major treatment option, and as chemotherapy, theoretically, is presented as a possible choice treatment, the precedence of surgical treatment had been challenged.

Implant or reconstruction is possible either at the time of initial treatment or at a later date. So far there have been no studies of the psychological effects of these options on women and doubts still remain about the desirability of encouraging women to take up these options.

IMAGE MAN-IPULATION

Of the whole group of women in the study only a small number (5) had some form of breast reconstruction, and/or conservation treatment. Significantly most of these had been

diagnosed within the last 5 years with only one woman insisting on breast implants 10 years after initial surgery. Woman on the whole did not take up the option of further surgical intervention for re-forming a breast after their initial treatment period (Dean et al 1983). Two of the woman had immediate implants, and one had immediate reconstruction, while two had reconstruction or implant at a later date.

"They said that they were going to give me something the that would be beneficial to me. If I wanted to ask any questions to phone up the L (breast treatment unit).

So I phoned up the L and they explained that they were going to build me up a, when they removed the breast they were going to build me up a new breast. so ah got that done. they took away part of ma stomach and built me up a new breast. And it was a plastic surgeon, Mr W who did it." Regina

So the decision had really already been made for Regina and presented in such a way that it would have seemed churlish of her to refuse. Not only were they going to remove the breast (and the cancer) but they were rebuilding another. Regina made it sound very simple, and she entered into it as such. In fact the whole procedure took some months and included two implants. She opted out of it at one point and this was accepted. She returned to complete the process and after two years and four separate operations she emerged with a clothed image that she was happy with.

The picture was quite different for women that themselves chose to try and get an implant or reconstruction. For women who had their treatment some time before it is quite another thing.

Although only a few women opted to go back and have further surgery many women in the group had thought about it and it was certainly a topic that was widely discussed. Those meetings which dealt specifically with this area were very well attended and would include women who did not as a rule attend group meetings.

Group E seemed to place a greater relative emphasis on breast reconstruction (related to the relative availability of reconstructive surgery in Manchester- again a result of a research project) and two of the women that were interviewed from this group were in the process of some form of breast reconstruction. A third woman, not strictly a member of that group, had attended the breast reconstruction meetings and talked to the women in the group who had gone through the process, as well as the mastectomy nurse. At the time of the first interview she had decided against it, but 12 months later she has had the first in the series of operations.

There was no doubt that the women in the groups were interested in the topic and found these sessions helpful, and they also provided the basis for some of them to make decisions about the possibility of they themselves opting for it.

On this topic the groups provide women with the information for action (who to see, where to go) but also with role models of that action. Some women went ahead and took issue

with the medics and managed at the end of the day to jump all the hurdles and to get what they wanted.

"I realised, after the group meeting, that perhaps that I could have an implant. I did go for an implant y'know... I went in January and had the first part done. I had the muscle taken out of my back. And the flap, I think they call it a "flap over" onto the front, and then a silicone implant. I'm waiting for the second stage now...I was thrilled to bits." Olive

Similarly,

"I think it was seeing her (a member who had had reconstruction) and the look in her eyes after she had had the implant. fantastic. Honestly, you should have seen her. When she came to the group y'know, she was radiant really. She was absolutely thrilled to bits. And when I saw the look on her face - that's what made me decide I would try." Nora

There was little doubt of the effect here, but it is important to point out that not everyone in the group was affected in the same way and they did not all dash down to their doctors demanding (sic) reconstruction.

Some group members remained adamant against reconstruction, at least for themselves.

"It's quite painful to have done I believe, two separate operations at least. and yet I know women who were absolutely thrilled. Do you know Kate? She said its the only thing that's kind of made her feel she's not had a mastectomy. But its not for me..no." Wilma

This compares with those women who pursued this option,

"It was for me. I just didn't like myself - could never like myself with what I'd had. What I was left with. I couldn't. I couldn't have foreseen, wearing that, having that..I couldn't throw it away you know (the prosthesis). Funnily enough I still have it in a box upstairs... I couldn't bring myself to throw it away." Olive

PARTNER'S REACTIONS

Many of the women commented on other people's reaction to them. Some were concerned about the effects on members of their families and a few expressed particular concern about their daughters. This area was not explored in the interviews in any detail, as indeed it warrents a full study in its own right. Of necessity for this work a decision was made to concentrate on a selection of the data. The most commonly related experience for women was their partner's reaction to them, and this is dealt with here.

A few women were not involved with partners and lived on their own. Some had always done so, and some were separated or widowed. None of these women became involved with a sexual partner during the time of the study, and therefore did not have to deal with physical intimacy that might include a revelation of the surgery scar.

Those women who were currently involved with, and who all lived with a sexual partner at the time of interview were not reluctant to talk about their partner's reactions - and

were often quite concerned about their partner's well-being. There were two women in the study with whom there was intense friction within the relationship - one woman leaving the relationship by the time of follow up.

Partners, like the women themselves were shocked and disturbed by the diagnosis of cancer. They often felt themselves helpless bystanders in the process of diagnosis and treatment. Some partners, apparently had difficulty in accepting the diagnosis, and in coming to terms with the treatment. From the accounts it appeared that the couple dealt with this crisis very much as they did with any other in their lives. Some women felt that it had brought them closer to their partners. Many women felt that they had to protect their partners from the worst of the shock. They did this by controlling their reactions and by limiting their own need to talk about the illness.

"He just did not seem to be able to take it in. When I was waiting, between the first visit and the next where they told you for sure, he could not talk about it really. He did come with me the second time, I don't think he quite realised the first visit. Mind you neither did I!"

"After they told me, they took him into a room at the end of the ward. I could see that he knew by his face, and the way he sat on the bed. He couldn't say anything, so I just asked him about Jock (the dog), and things like that. Before he went he said, 'It will be alright, won't it?' So I said 'Yeh, it'll be alright.'" Chris

Many partners took an active part in making any decisions and offered all the support that they could. But women always felt that it was up to them in the end.

"We did, we discussed mastectomy, even before we really knew it was cancer. But, oh it felt there was no choice, not really. I felt he didn't want to say."
Vivienne

Partner's reactions to the scar was important - and women were anxious about that. In an effort to make things easier for their partners they made every effort to quickly adjust to the wound/scar themselves.

"I never realized how big the scar would be. You can't really visualize it till it happens to you. But I couldn't visualize how it was going to look and the nurses did explain it but I don't think I took it in. You'd be better with a diagram really, but I suppose they'd think that would frighten you because it's like a big scar you know."
notes

This type of reaction was fairly typical, where women would have no idea of how they might look after surgery. For some women the scar was not as bad as they had feared.

Attempts were made, in some hospitals to get women to look at their scar before they left hospital. On occasion, partners were also encouraged to take the opportunity to face "the scar" in the hospital setting. This depended on the attitude of the consultant, rather than a coherent policy in the treatment of breast cancer.

"The surgeon said ... 'Let's have him in - have you seen this?' It was this doctor's way. He thought you should share things ... I think that was the first time he'd seen it ... It's going to take time - for us to get back to normal." Carol

In most cases, couples did not have the opportunity to confront the physical changes in the hospital, but would do so after the return home.

"And when I was in hospital he (husband) never asked anything about the scar or stitches. And I thought oh - he's running face to the wall ("squeamish"). Yet as soon as I came home, and went upstairs he followed me straight up and he said "Let's see it" and I feel that he geared himself up y'know - now or never situation.

The day I got home it was the first time I'd worn the bra and stuff and I went upstairs to take it off and he followed me up and said "Let's have a look at it then" and that was it." Sonya

It seems that in both these instances, as in others, the partner had come to some decision by themselves, and had adopted a strategy that was acceptable to both them and the woman they were involved with.

Going back home allowed privacy - but also put some pressure on intimacy which was avoidable in the public sphere of the hospital. This move from hospital to home was often a time of crisis and a time when indications about future "life" were apparently important for both partners.

In addition women had to deal with the reactions of other family members, and friends. They faced a mixed response here, with some people seeming understanding, others remaining awkward, and avoiding contact. Many of the women used humour in these accounts and would describe how they joked about what had happened. One woman had a story she told in social situations that she felt helped deal with awkwardness.

"I sort of try and say something that makes them feel better, like I tell them about when I was going along the High Street, and gave money to, I don't know.. Barnardos or some such. And they had those wee badges, but they weren't sticky they had a pin! And the struggle I had trying to get the wife to not stick one on. I thought they (prosthesis) might explode! " Bessie

Overall these women had gone through the whole process of diagnosis and treatment for breast cancer while relatively uninformed about it or the procedures they were put through. Subsequent to that they sought out the self help group, often in an effort to reduce their feelings of isolation and in an attempt to put their own experiences into some realistic perspective. As will be clear from the above accounts, women frequently felt objectified by the medical process, and their psychological and emotional needs were persistently ignored. They moved from well, and fairly active women to patients with a potentially terminal illness by a rapid and confusing procedure that did nothing to validate them as people of worth. They emerged from this experience to find themselves frequently worried and isolated, but fearful of approaching the medical professionals with seemingly trivial questions about aches, pains, limits, appearances etc. As there is nothing in these data to suggest that these women are different from any other women who go through this process, one wonders where, and how, the majority of women, who do not attend group meetings, deal with these issues.

AT HOME

Once the hospital stay was over and the physical surgical treatment had been completed, it remained for that person to deal with the other issues surrounding the disease on their own, or within their own social network. They no longer had a professional body that they could turn to. They were aware of the time constraints of a GP consultation and they often had no other source of reference for their health worries. Whereas previously they had a wealth of medical opinion in hospital now there was nothing. It was at this stage that the women began to look for a reference group they could relate to, even though it might be some months before they could face the public-ness of an actual group meeting.

The women now returned home and had to confront everyday life again. It seemed that initially this move away from the "safe" environment of power and knowledge of the hospital was softened by the attention and care of family members and friends. The medical surveillance was continued via check-ups but no provision was available to help women to come to terms with the disease diagnosis and the changed image of themselves, and their everyday lives - which now had to include cancer.

This was undoubtedly a difficult time. Generally people seemed to feel at their lowest four to five months after returning home. There came a time when the drama was over and everyday reality had to be faced.

"It was about two months ago when it hit me - that I was going to be like this (one breasted). Its at night-time when I have to undress - and every day, I thought, I'm going to be reminded. Everyday of my life." Liza

So the visible bodily changes served as a constant and almost inescapable reminder of the diagnosis of cancer. It was certainly something that women, on the whole, had not thought about previously or maybe they had not had the time or inclination to think about it.

The same woman continues..

"..thinking of the operation you think, "I'll heal" and you'll go back to normal. Well you won't go back to normal." Liza

Bodily changes seem to reflect other changes for these women - that things would *never* be the same again, that something had happened that had wrought unending repercussions in their lives.

"Ah wis coping - it wis done and that's all there was to it. Y'know you never get over it. Something's missing, that sort of thing..." Sheila

and

"Most days, as Ah say, it doesn't bother me. And as Ah say ma husband is very very very good. Ah've accepted it. Well, you don't ever get over it - but you accept -you are..yes." Geraldine

Only in the context of the intimacy and the exploration of the research interview did women expressed such feelings, and occasionally in the group setting. Somehow they had learnt to cope with these feelings and found a way of living a life.

"I mean I said it at the beginning, right at the beginning - I said 'I can do without a breast.' and its no worse than breaking a leg, or loosing a leg. You have to go on with the rest of it.

But I think it just hit me (when undressing) the fact that.. I don't know. It could have been worse. But on the other hand I've had to bring myself round to say, well, I'll get through with it, hopefully. And the group has helped there" Ursula

The groups did address these issues directly, in sharing and normalising experience. Efforts were made within the group context in particular to help women with the disguising of their breast loss. On several occasions make up demonstrations featured in group programs, both facial make up and make up that covered the scars of surgery or the burns of radiotherapy.

One woman went along to her first group meeting,

"The first one I went to was a make up demonstration. And appearances are important to women who have had this particular operation. Y'see, because you feel pretty ugly y'know." Tanya

So the make up was not an additive to highlight but something to obliterate or to cover up that which cannot be directly mentioned.

The following interchange took place at a mastectomy group meeting. T proposed that the group invite someone to give a make up demonstration,

T: "...its the sort of make up to cover up scars - not face make up."

A: (sotto voce) "What could cover that up?" notes

FEELINGS OF MUTILATION

"YER NO AWE THERE"

One of the most profound aspects of mastectomy was the sense of mutilation. Several woman used the word in connection with the operation - ranging from those who felt angry about it, that it was unnecessary and who did have to cope with large scale dis-figurement...

"I never knew it was going to be like this. I've a scar right across here, and half way across my back. I cave in here - and its a real mess. They've mutilated me, that's what they've done." notes

to women who had what they themselves regarded as minor scarring from simple mastectomy and who felt that they had been included in the decision about surgery...

"I know it is vain. But you still feel, I don't know. You don't feel a woman at all when you come out. You feel very low. I don't know, mutilated I think." Olive

Througout the interviews women used the word 'mutilated' as well as others like 'malformed' and in one instance 'crippled'.

This sense of mutilation, was something that women felt not only affected their totality but hit specifically at the image of themselves as women. The images surrounding breasts in this country and their significance in the male-defined presentation of women as whore/mother is extremely pervasive. Many women felt that they had lost a part of their feminine definition.

"But its very difficult to still think of yourself as essential woman when you look down and see your outline. it is very difficult and that, I think, is the hardest part. Now there will be a lot of woman who will say no, it doesn't bother them. But for me I still find that very difficult... I'm sure quite a few do, but its something that a lot of women may not want to divulge or even to identify - or talk about." Lena

Thus Lena was able to acknowledge what the breast loss meant to her at that time, 10 years after the operation. And it was still a recurrent theme in her life - confronting herself as an image of femininity. However this was not the only way that she analysed it. More far reaching for her was the idea of herself as whole.

"I still find, y'know, when you watch something on television, and you think, "Wow, that's a beautiful scene". But its a perfect thing because everything is intact. Now you look down at yourself and you think (sighs) I can't convey that, because I don't feel that totality now. and I don't, I really don't. And that has left its mark on me." Lena

The "totality" that Lena expressed here was something far deeper than a visual image. There was no doubt that the experience of cancer in her 'intact' body had added to the dissection that had been further confirmed by the mastectomy. This was what women had to deal with. (And it may be so for all women and not just those experiencing breast cancer and mastectomy.)

Women were certainly influenced by media presentations of women as bodies.

Several women mentioned the overt pressure to be perfect as displayed in the media - and it was much more than passing concern.

"Well that hurts after a mastectomy. The adverts did. I've always envied them. This is the point. It wasn't anything different to me. I've always thought I wish I had a figure like that. But knowing, now you could never have a figure like that. Before you could have had plastic surgery and had a figure like that, but afterwards, you knew you could never have it. Its gone y'know, and that is horrible." Kirsty

and

"Its like you open the newspapers, and all you see is boobs all the time. And eh, sometimes it hurts and reminds you,... I don't think you ever forget it ... It doesn't worry you as much after a while." Liza

So these women are persistently reminded of the change that has taken place in their body/figure, both through the health impact of the disease. They are constantly presented by images of women's bodies where the greatest emphasis is placed on breasts. They remain the most publicised and abused aspect of female anatomy.

As regards the use of the actual term "mutilation" one professional speculated about its origin, its current use and its position in the understanding of mastectomy.

"I don't know when it was first used, whether it was first used by women who felt, y'know. When surgery was in its infancy. I mean a radical mastectomy 30 years ago was something nasty. I mean you didn't reckon to get proper use of this arm back ever again. I mean if it were on this side.

The thing about those women in that room on Monday (a collective meeting of three self help groups) most of them had a, well not exactly a carefree, but a relaxed attitude, hadn't they? They had found a life they could enjoy.

So whether it comes from.. whether its a word that has entered the language from the medical side" ward sister

The amputated breast becomes not only a part diseased flesh - but the breast itself is minimised as less important than a leg, an arm, and by one woman her head.

"I mean, that's what I've been greeted with "Well, its just a boob!... There's nothing you can relate to in the same way as a man." Lena

This section of this chapter focuses on the psychosocial reactions women went through on their return home. An attempt has been made to underline the complex relation, for women, between body image and image of self and the disruption in both by cancer and cancer treatment. Women coped with the dis-figurement by trying to cover it up -and to present a "normal" appearance. To this end they made careful use of prosthesis, clothing and for some, breast reconstruction. All of these were areas addressed by the self help groups, and forums where such information was available.

SUMMARY

This chapter has traced the experiences of women from the time of first contact with a medical professional in relation to the symptoms of breast disease through the diagnosis and treatment of breast cancer. Of necessity only a small portion of the available data has been utilised, which reflects the diversity and richness of the women's response to the study.

An attempt has been made to trace through the most common experiences of women, and to highlight the underlying difficulties apparent in all accounts of communicating with, and obtaining information from medical staff. It appears from these data that the medical process, once initiated, was competent and efficient on the whole, but the attention to the psychosocial dimensions of the disease was poor. This study was conducted some time ago and some services have changed, but none of these women were offered any "proper counselling" and their psychological difficulties were never overtly acknowledged. This, essentially sets the stage for the self help groups, given the importance of the psychosocial dimension for the women involved. However, as will be seen, the groups had very little direct influence in this area, and they were cautious about it, not wishing to be seen to interfere in medical management. Access to speak to others going through these experiences were strictly regulated

by professionals. The role of the group remained an attempt to put the experiences into context and to work with professionals to facilitate better communication in general rather than specific intervention.

Women remained essentially passive in receiving health care, and were fearful of being demanding in the hospital setting. When they came to the point of transition between hospital and home, they still had to deal with prosthesis and the reactions of others. For subsequent prosthesis fittings women were better prepared in terms of knowledge and assertiveness through their contact with the groups. The groups often made contact with the local prosthetic supplier, to mutual benefit. For those who later considered breast reconstruction, the groups again were sources of information, and support. This was an area that they were more confident in, as it did not challenge the clinical expertise of professionals.

It was when women returned home to the everyday reality of facing life with cancer and a radically changed body image that they were most likely to seek out help from others in the same situation. They were unlikely to take their concerns to anyone in the medical system, their experiences had reinforced that their personal concerns were not 'medical' and therefore not likely to be dealt with in that setting. To some extent the groups were part of the attempt to change that, but at the time of this study their work was primarily support for members.

Already the influences on self help groups in defining their boundaries are emerging. The groups tried to highlight the psychosocial aspects of their experiences without seeming to challenge clinical decisions and management. Their relations with professionals and their attempts to legitimise the groups are persistently influenced by these themes which they learnt through their own experiences within the health care system.

The first section of the next chapter examines how people came to hear about the group, and what prompted them to make contact.

CHAPTER 4 : GOING TO A SELF HELP GROUP

This chapter contains details of each of the groups involved in the study. The chapter then goes on to look at how people came into the groups, and the next chapter looks at participation in the groups.

Information is presented about how each group started and its first meeting. Details are given about the group's current structure, and its interactions with professionals. The different types of meetings and other activities are detailed in appendix i. These data came from literature and leaflets from the groups, as well as interviews with members and from the participant observation notes. Some care has been taken to keep the groups anonymous, but group members and local professionals will be able to identify the groups from the information given. Any reader identifying a group is entrusted to keep sensitive information confidential.

GROUP A

START

Group A started only a few months before the beginning of the study in 1983. The main impetus came from one woman, Vivienne, who had been diagnosed with breast cancer after several years of benign and painful breast cysts. Although she felt that she had been treated well within the health service, she had been surprised by the lack of communication and support available both during and particularly after her operation. She felt that she wanted support from other women too, and began to look into the possibility of setting up a support group about three months after returning home. She had made contact with the local mastectomy nurse as well as a variety of medical professionals. Her enthusiasm was greeted with some reserve. In the same area a mastectomy support group had been initiated by a group of professional workers the year before, and it had floundered. The reasons for this were not clear, except that numbers dwindled, and the professionals involved did not have the time to keep the group going. In the event it seems to have hardly got off the ground.

Vivienne, therefore had to take this history on board. She worked with the mastectomy nurse, to ensure that she was not "treading on their toes". The nurse gave her the names of woman who had shown interest in the group the previous year. She also made available some of the proposed topics for the group, and eased the way for Vivienne to approach potential speakers.

A date, time and location (a local hotel) was arranged for the first meeting, and an advert was placed in the local paper. Women were also informed through the local breast treatment unit, and a variety of professionals invited to attend.

FIRST MEETING

The first meeting seemed to have gone well, and at that meeting a committee was selected to organise and promote the group and date etc of another meeting arranged. All in all over thirty women came along, and seemed to get something out of it. Women commented..

"I've learnt more here in an hour than I have in the five years I've had it"

"I never knew there were so many other people with this"

"I didn't want to come, but my sister made me. I'm glad I did and I've met such kind, understanding people." (all from notes)

Many of the women who came to that first meeting did not come on a regular basis, and some of them did not come to the group again. However about twenty attended the second meeting and things went on from there.

The mastectomy nurse and a local surgeon attended the inaugural meeting. The latter pledged some money (that had been allocated to the original group the year before) if the group was still up and running in a years time. The nurse maintained some contact with the group through successive meetings, but played no active role in the structure of the group.

Thus the pattern was established for the group with local professionals. The group was seen as operating alongside the formal services and overtly supported buy individual professionals. The nurse counsellor, in particular, gave some time to the group, and let it be known that she would be available for help. The management of the group remained in the hands of the women who were also its members.

CURRENT STRUCTURE

MEMBERSHIP

The group kept no detailed account of the membership for some time. They struggled with the dilemma of infringing on women's right to remain anonymous, and its consequence for publicity etc. In the end they opted for a voluntary system of names and addresses. This seemed to work well, with some women requesting to be on the mailing list, but not attending many, if any meetings.

All in the group were theoretically regarded as equal members, and encouraged to take a part in the group. The committee, which consisted of seven women, including the usual offices of secretary, treasurer and chair, was set up. Vivienne occupied the latter, and remained the leader of the group. She found it difficult to delegate tasks, and saw herself as crucial to the group and its survival. She combined this with an apparent resentment of the burden that the group and its management placed upon her at times. This proved difficult for other members of the group, so that if they volunteered to do tasks, it was over-ridden by Vivienne or else their efforts were criticised by her.

Her autocratic leadership style was recognised within the group as a coping mechanism (for her), and many of the other women worked their way around it. However it did de-skill many of the women, as well as ensure that the group did survive in some form. This was also recognised by professionals in the area, and they did attempt to help out by encouraging and supporting some of the women in their efforts. One, the director of the breast screening unit, also tried to talk with Vivienne, but to limited avail.

This style of leadership was also noted by other groups in the area, and at interview they made comments on it, indicating that their group did not work in the same way.

CONTACTS WITH PROFESSIONALS

The group maintained contact with a variety of local professionals. In particular they sought the help of the specialist nurse in the breast treatment unit, and the director of the breast screening project. They had a selection of local specialists to speak to them, including radiologist, surgeon, hospice nurse etc. Once established they attempted to maintain these links, and would keep these people informed about the group.

The group received very few referrals from professionals. Indeed none of those interviewed for this study had been referred into the group by a professional. On the whole the group seemed to feel that where they had links with professionals, these were reasonable. But that they would have welcomed greater, and more regular contact.

They were proud of the contacts they had with professionals, and clearly magnified these contacts as a means of legitimising the group. The group attempted to run alongside professionals, but with some input from them.

GROUP B

START

Group B, which was based in small community outwith the city was part of a larger national organisation of cancer self help and support groups. This particular branch had been set up by two enthusiastic women (Ethel and Lynda) who had both received treatment for breast cancer. Initially they had attended a group in the city, which had been part of the same national organisation. This had closed because of leadership difficulties when the original leader had died. But even prior to that, Ethel and Lynda had arranged to start their own local branch. They found that more and more local people from their own area were travelling into the city to attend that group, that it made sense to them to start their own group.

They contacted local people whom they knew and invited them to the first meeting of the group. It was held in Lynda's house, and group meetings continued to be held there. No professionals were invited to or attended the initial meeting.

FIRST MEETING

The first meeting took place in June 1981 and was well attended. They received some help from their colleagues in the city group, and some contact from the national organisation. On the whole, though, they 'just got on with it'. Their main aim was to provide local support and the group was set up to be very informal. They were obliged to fulfil the roles of chair, treasurer etc. because of the national guide-lines, and this was carried out in a very low key way.

CURRENT STRUCTURE

MEMBERSHIP

The group had over thirty registered members, although around 7-14 people attended the group meetings. The guidelines of the national organisation made them obliged to keep note of members names etc. although this was a mere formality. This was shared in the group meeting, and indeed provided a means of reviewing and hearing about members who had not attended for a while. As a local group they all knew each other in some capacity or another even before coming along at the group.

The group also encouraged relatives and friends of people with cancer to join and to attend the support meetings. The group was not restricted to women with breast cancer.

The 'leadership' of the group was clearly in the hands of Ethel and Lynda. They held the offices of chair and secretary in the group. However, they were keen and capable in delegating tasks and activities to other group members in a supportive way. Indeed, for Lynda the tasks of a group were a new experience for her, and other people were encouraged by her hesitant determination in tackling her 'duties'. Ethel had worked in a setting that had already provided her with organisational and leadership skills, and this helped the whole group.

All the group members participated in some way or another.

PROFESSIONAL CONTACT

Group B had limited contact with professional people. They did have invited speakers, and maintained low profile contact with the breast treatment unit specialist nurse. Local GP's featured on their guest list, as did the usual array of surgeon etc. However, unlike some other groups they did not make much of these contacts. They did feel that they were a bit neglected by professionals. They pointed out that professionals came and gave talks and seemed to like the group, but then they never made any further contact, although they were happy to return again. This group would have liked more input from professionals. They felt they were a bit isolated, although they did not want to operate within the formal services.

Most members came into the group through local contacts. However the mastectomy nurse had given the names of a few people to the group to establish contact. These referrals were seen as unsuitable for the group. Most of these referrals were people who were terminally

ill, and Ethel commented that "no-one could do them any damage". This was not an experience unique to this group. This confirmed the group's impression that professionals did not really know what the group was about.

GROUP C

START

The origins of this group lay in the local Breast Association. This began when a group of local women (described as "hospital auxiliaries and cleaning ladies"), one of whom had diagnosed cancer, got together to raise funds. The idea was to buy a scanner for a hospital, or else to fund a mobile mammography unit for local women. The women were successful in raising several thousand pounds, and harnessed a great deal of local support including local businesses and the Masonic Lodge.

They then approached a local doctor for advice, and two medical professionals visited the women to talk about options. The cost of buying and running a scanner was prohibitive, and outwith the capabilities of a small group. Several options were discussed, including the possibility of a local facility for women with breast problems.

The local Breast Association was formed and a clinic set up in the local health centre that was to ..

"..provide help in prevention and treatment of breast disease and to aid all those with fears and anxieties with breast problems."

The clinic was run once a week by a nurse (Frances) who was employed and trained at the breast screening unit and local treatment hospital. This nurse was therefore available for women who self referred to the service, and she had a specific educational remit. Thus, for example, she gave talks about breast screening at local businesses.

The numbers at the clinic were steady, but small, except when a local firm would enable its workers to attend. The clinic gradually came to perform yearly checks on women, and Frances felt that this was not its primary function. Women were not gaining in confidence about breast self examination, but were becoming dependent on a medical service. In addition, a brief review of the clinic records suggested that it was young women (in their early 30's) who were attending, and not the older women more at risk.

In addition Frances received referrals from the local breast unit of women who had received treatment for breast disease, as well as referrals from local GP's and health visitors. The case load eventually built up and Frances wondered about helping the women to help themselves, which would also help her deal with the increasing work load.

Group C began when Frances organised a meeting in her own house, inviting 30 women to attend. She maintained a role as a professional, but was fairly successful in enabling the women to take over the main organisation and day to day running of the group.

FIRST MEETING

Of the 30 invited to the initial meeting, in 1982, six women arrived. They had all been in contact with Frances recently, and all had cancer diagnosed in the last year. They met in the afternoon informally. They discussed whether a group might be feasible and beneficial, and what it might do or include.

In particular, they talked about the cancer focus of the group. Some members were adamant that the group should not be called 'anything like mastectomy something'. This was felt to be related to with living in a small community and avoiding stigma. They agreed to meet up again, and to develop a program that would include a variety of talks and events that were not all cancer related. They changed the time to the evening, and thereafter met on a monthly basis.

Frances continued to be involved, and the group was seen to have some connection with the Breast Association.

CURRENT STRUCTURE

The group gradually developed and changed in line with the women's needs, but maintained the connection with Frances. It gradually came to be seen as more independent of the Breast Association, and certainly maintained financial independence.

MEMBERSHIP

The group kept no detailed accounts of membership, but did have a mailing list. They were open to any woman with diagnosed breast cancer, although there was at least one relative involved.

A committee was formed and the women on that took increasing responsibility for organising the meetings etc. Two women, in particular, took an active role here, but any member who was interested was involved in organisational issues.

The group indicated that

"..what we are trying to offer is sympathetic friendship from people who understand what you are going through."

It was made clear that no-one was qualified to give medical advice about treatment but that Frances would help with medical queries, or point you in the right direction.

CONTACTS WITH PROFESSIONALS

The group programme suggests that this group tapped into the local expertise in much the same way as other groups, inviting local professionals to talk at the group meetings.

In addition the group was always attended by the nurse counsellor (Frances) who had initiated and continued to support it. She made herself available to women who might want to talk about individual problems, and often referred them along to herself in her more formal professional capacity, or to other professionals. This seemed to work out well in the group, and there was never a feeling that the group was only about access to the nurse. She remained available at the local health centre on a weekly basis.

The group and Frances seemed to have managed a compromise in the amount of input Frances had to the group. The members played the largest part in running the group and in making decisions about the group policy and programme. The nurse counsellor, however, was essential to the group. It was also seen as still part of her job, that she was paid for. She made it clear, however, that when the funding for the post ran out, as it was likely to within the next 18 months, she would continue her involvement in the group, but might have to reconsider her role. She managed to facilitate the group in its development in such a way that the women in it gained in self confidence, and took more and more decisive action. Thus the group managed to remain outwith the formal services, run alongside them fairly independently, with a professional worker.

GROUP D

START

Group D was started by two women who had both had treatment for cancer. They had attended another group in the city, and one of them (Nina) had held an organisational position in it. They both felt that they wanted a group that functioned in a slightly different way. A series of events then precipitated the setting up of a new group. In particular the chairman (T) of the group resigned under a bit of a cloud, and the post was offered to Nina, who refused it. Then the chairman took back the post, and accusations were made against Nina. She described how she felt that as he was reinstated 'he had to be seen to be doing something'. Both women felt that some of this upset was due to the progress of illness in the chairman, who died within the year.

Some members of the group had started meeting in Nina's house, in private initially. Some people attended both groups, and the new group only became public after T's death and the demise of the original group.

The new group was different in its intensity and emphasis. The members were keen to meet more regularly, and to provide stronger support for each other. They were also keen to develop ways of approaching pain, and aimed to eventually provide a forum where people could develop through illness and death, as well as the circumstances for them to eg. have holidays. It was also explicit in their conceptualization of the group, that they intended to

expand nationally. They had clearly experienced gaps in the service that they were prepared to take on themselves as no-one else seemed likely to.

The groups' own booklet, of January 1985 states that..

"This group began in 1980. A few cancer patients, relatives and friends, met as a means of mutual support, with the positive idea of personal growth in spite of difficult health circumstances.

...There is at once a need for a new lifestyle which is suitable and satisfying, and the facing of the break with the old. We found that new friends with similar problems helped with finding the answers.

At first the group limited itself to cancer, but now it opens to anyone suffering from stress and pain associated with any type of illness."

FIRST MEETING

It was difficult to pin-point what actually constituted the first meeting of this group. Most of the details are available in the above section.

CURRENT STRUCTURE

Of all the groups this was the one that seemed to move the fastest in terms of its development during the time of the field work (as well as thereafter). It was a registered charity, and produced a comprehensive booklet which included not only the next program of events and meetings, but also details of the management committee, progress report and finances. The philosophy of the group was outlined in a series of accounts of the counselling service, therapeutic art etc. The group's backing was evident in the listing of the qualifications of the main contacts and statements by members.

MEMBERSHIP

Membership of this group was not restricted to those who had experienced cancer, but was open to anyone who suffered pain. The name of the group identified its function as adapting to and learning through illness. At the A.G.M. in Sept 1984 the membership was 70 which was substantially increased during the research period. Meeting were variously attended by anywhere between 5-40 people.

The two group initiators played the main role in organising the group, and easily incorporated help from other members. Thus quite a few people in the group played some part or role in the management of the group. People in this group were generally more disabled than participants in other groups, and the membership came to include not only relatives and friends but also volunteer drivers and helpers.

CONTACTS WITH PROFESSIONALS

The group had an explicit remit to co-operate with professionals..

"It is our intention to extend the links we have with professional carers, such as doctors and nurses, social workers and health visitors. ..The programmes

show our present contacts with the medical and paramedical professions, housing experts and the social work area of counselling. We have links with most denominations of churches through group membership and professional concern."

The group certainly had an impressive array of local professionals on its management committee and listed 'Medical Advisers' in both Psychiatry and Medicine. The Regius Professor of Clinical Surgery was President.

The policy of the group was to enlist as much professional support as was possible, but without compromising their principles of self help. During an interview a leading member indicated that professional people were under constraint, and that they found it hard to move to the self help model.

"They (professionals) can't help it, and you really can't blame them, but they do try and impose professional criteria. Its almost something that you cannot escape. They work from a different model, and there are certain pressures on them. This makes it difficult for them to attempt another solution, to do things differently. Within this group the sense of "obligation" is entirely different, and almost in contrast to what is understood as the same within professional work." Sarah.

Thus the group leaders, and the group, had a comprehensive grasp of the benefits and difficulties of relating to professionals. They were able and prepared to work with that. They were determined to maintain their position alongside formal services, but were aware that required a change in attitude from professional workers.

GROUP E

START

Group E was originally set up in 1981 by four social workers. Their posts had been jointly funded (by social services and the health authority) initially to allow work with out-patients, pre-operative ward work and post-operative follow up. Pressures of time meant that those in post concentrated on the latter two areas.

The group's beginnings were detailed in a variety of social work reports that were made available for this research. All quotations in this section are from these papers, unless otherwise indicated.

The aims of the group were clearly stated,

"The purpose and objective of a self help group would be sharing information on coping with various aspects of the operation and its consequences. It is also intended to offer practical help."

The group was set up partly in response to new initiatives on the breast surgery ward (although this was never publicly acknowledged). Nurses had been trained to detect psychiatric and psychological difficulties in women going through surgery for breast cancer and this was being evaluated by a psychiatrist.

In addition an information pack had been devised for women and this was also being monitored. Thus the role of the social workers on the ward had been somewhat constrained, and the self help group was a way out of that. It was accepted that it did not interfere with the on-going research project. It was seen by the social workers as a way of reaching clients and of changing the face of social work. Thus they felt they were less constrained by a popular image of social workers dealing only with poor and deprived individuals.

There had always been an intention to evaluate the group. This was clearly stated in the aims of the pilot project.

"To evaluate the effectiveness of such a forum and advisory service, primarily because we are not aware of any such evaluation, and which we felt would be of use to any future group starting. Secondly, as workers in a health setting we are aware of the *need for credibility* in starting something that the medical profession would view with foreboding, in order to avoid active opposition to our method of working."

Three consultant surgeons at the two local hospitals were approached to allow referral into the group. One refused to participate. Eventually a pilot group was set up, with six women randomly selected to attend. A committee was set up of participants, three social workers and a specialist nurse counsellor.

Interestingly, the role of the social workers was delineated from the start.

"We anticipate that although the group would become more self sufficient, it will continue to expect the back up of the social workers and the mastectomy nurse."

This seemed to be mainly in response to a monitoring function of the social workers, and their continuing sense of being held accountable.

"(our role)..in hospital and social services means we have a responsibility to ensure that the group is helpful and not damaging and therefore we would expect to continue to be involved."

To a great extent, then, the group could not be seen as really self help as the main organisers and controllers were not the women themselves. Yet the group persisted in referring to itself as a self help group, mainly because of the emphasis placed on the sharing of personal experience.

The original pilot group was deemed a success, although no actual evaluation was written up. Certainly the women wished to continue, which is arguably the best indication of successfully providing a forum for on-going support.

What was recorded of this pilot group highlights the role of the workers and their tentative response to the women's needs. A policy was initially adopted of staying with 'safe' topics, but the group pushed onto other areas that had initially not been envisaged as appropriate. So there was a shift in emphasis . . .

“(from) topics such as prosthesis and clothes, we had moved on to talks of breast implants, research on causes and treatment of cancer, and the effects of mastectomy on relationships. This was done in response to the wishes of the women themselves.”

The group therefore continued, but it was not too long before the original workers moved on and by the time of the current work, there were two new social workers in post.

CURRENT STRUCTURE

MEMBERSHIP

No detailed account of the members of the group were made available to the researcher. The social workers did keep a note of who was in the group, and all in all there were about 25-30 women. The group was restricted to women who had diagnosed breast cancer, and who had been treated in the main professorial unit. Some of the women came quite a distance from other areas in the city.

Some of the women were notably more involved than others and had taken up roles in the organisation of the group.

CONTACTS WITH PROFESSIONALS

From the introduction about the start of the group, it will be clear that the group was more or less run by the two social workers, with the mastectomy nurse attending meetings on a regular basis.

The new social workers were less familiar with the group set up than its originators and indeed found the group quite difficult. They were unclear about the limits and extent of their role in the group. The policy of the newer workers was to move the group toward a more independent, self sufficient mode. This they attempted by getting the women, and the committee, to take on more of an organisational role. However this conflicted with some social services policies, and this led to difficulties. For example, the group was held in social work premises. This meant that a social worker always had to be there, and they had to take responsibility for opening and locking up.

At the time of the field work the social workers had only given over to the women the organisation of refreshments and the chairing of the meetings. The social workers remained wholly responsible for any individual problem solving and liaising with health professionals. They shared jointly the overall responsibility, organising meetings and group funding. However it was notable that the women in the group often resisted these attempts to push them to take more responsibility. It seemed that once something was defined as the role of the professional worker, it was difficult for the women themselves to take on that task. The group therefore maintained an uneasy balance where it was not seen to operate within the formal services, nor was it entirely self help.

The part played by the mastectomy nurse changed as the group progressed. Initially she had not been considered a 'worker' in the group, but being invited to meetings had attended, and then taken a place on the committee. She felt that her role was uncertain as far as the formal set up of the group was concerned. However in the actual functioning of the group she played an important but low key, role. Women knew she would be at meetings and would approach her to talk about health issues that were concerning them. She would advise, refer on to herself at the clinic or onto other sources as necessary. Often those approaching her needed reassurance that they could go to the doctor and take up his (sic) time. She did not get into the dilemmas that the social workers felt, mainly because she was not organising the group. She maintained her role as a professional with input to a 'self help' group. She was there by invite, not necessity.

Thus the group also played a part as a primary health care resource. Indeed the nurse felt that women used it far more than the formally arranged clinic that she ran. The informality of the contact eased the way for discussing problems. This role was recognised by the social workers.

The group had contact with a variety of professionals in the role of speaker. Initially these were organised by the social workers or the nurse, but the women themselves were being encouraged to take on this role.

GROUP F

START

The founder member (Mat) of this group had Hodgkins' Disease 10 years previously. He had coped with it in a variety of ways, but continued to find himself full of uncertainty about the future. When he decided to complete a long, well known walk for charity, he looked around his local area for a suitable organisation which helped people with cancer, and found none. He talked to a variety of local professionals, who seemed to offer support to people on an apparently idiosyncratic basis.

The walk was completed and the money raised was used to fund a twelve session course for professionals to help people with cancer. But still there was nothing organised for patients. Mat attended the course himself, and learnt a lot about counselling and group work.

Making the decision to start a support group that was not dependent on professionals went a little beyond what those organising the course had envisaged, and was moving faster than they wanted. Mat started looking for publicity, first with a radio program and backed up by local papers. The first meeting was therefore well publicised.

FIRST MEETING

The initial meeting was organised locally and 30-40 people turned up. Before the meeting Mat had made personal contact with other people with cancer through a social worker, as well as the media publicity.

The meeting allowed people to talk about what they wanted, and they set up a committee with Mat as the organising chair. He played a role in selecting people onto the committee, and chose people with energy and direction. The group went on from there.

CURRENT STRUCTURE

PROFESSIONAL CONTACTS

The group was supported by a wide variety of local professionals, from social workers to psychiatrists. They helped with the training of telephone volunteers, and a selection of them also acted as back up for the telephone line, ie the volunteer could phone up for advice and support. Some of the professionals attended the monthly support meetings for volunteers.

There had been discussion in the group about the role of training, as some members felt that the personal experience was enough. The group were certainly aware of the difficulties of 'professionalising' their support, and were keen to avoid being 'mini-professionals'.

The group had a variety of professional speakers at their meetings, as well as interested professionals sitting in on the meetings. Some members of the group were also health professionals in their own right and, where appropriate, used their professional skills in the group.

The group managed to maintain good, supportive input from professionals and was aware that this was a balance that had to be maintained. They had chosen their professionals carefully, and were clear that they were not part of the professional system, but were keen to work with professionals.

SUMMARY OF GROUPS

Thus the groups were, in brief,

Group A - A breast cancer group, set up and run by members with some input from local professionals. It was still in its first year of existence at the time of the study.

Group B - A rural group with both men and women - a general cancer group, but with a strong orientation to women with breast cancer. It was part of a large national organisation, and had very little input from local professionals. It had been in existence for over three years.

Group C - A group situated in a small town, that was run along self help lines, but initiated by a local professional who maintained a key role. It had been going for two years.

Group D - This group emerged about three years prior to the study, and had moved from a cancer group to include people with chronic pain. It was initiated and run by members, and expanding rapidly. It maintained co-operative relations with professionals.

Group E - A breast cancer group set up by professional workers to run along self help lines. It had been going 2-3 years, and the workers were looking to make structural changes to move it towards a firmer self help model.

Group F - In existence for about three years this group had developed rapidly to include relatives and friends of people with cancer. There was a well organised back-up of professionals involved in support and training.

There seemed to be as many differences between groups in each location as between locations, and this mode of analysis seemed unfruitful. More interesting were the workings of those groups initiated and run by professionals and those which were self run. Groups C and E provided examples of the former, one group being located in Edinburgh, the other in Manchester.

The next section will look at how people came into the group and their expectations of it. The next chapter details members involvement and their views of group benefits and drawbacks. The groups' interactions with professionals, and its effect on some of these activities will be considered.

WHY GO TO A GROUP?

There was no way of knowing from the data how many people knowingly chose not to go to a group, and what their reasons were for not going at all, or for maybe going once only. Similarly it is impossible to estimate how many people knew about self help groups, and how many did not. These are important research questions but they could not be addressed within this study.

From these data it appeared that there were many reasons why people sought out a group at any particular point in their experience, but it was certain that people tended to act when they were out of hospital and back at home. Some people said that in retrospect they would have liked to have *known* that there was a group around and the possibility of someone to talk to at the time of diagnosis and initial treatment. Few people actively sought out a group at that time, nor did they usually know one existed through their contact with professionals.

This was an area that some of the groups were trying to open up. However, as the consultants were determined to maintain control in the hospital setting, they were making very limited progress. In those groups that were 'run' by professionals (ie group E, and to a lesser extent group C) the information about the support group was more readily available to women at that time. Nevertheless, even in those groups people tended to wait until they were back at home before making contact with the group. The fact that most people seemed to want the

reassurance that there was something there and not necessarily to use it was indicative of the need for general support at the time.

Although the literature suggests that people set up and seek out self help groups, because primarily, there is a lack or gap in service provision (eg Williamson (1983), Kleiman et al (1977)) a few writers have looked at other factors (Sidel and Sidel (1977))

These data do not support the suggestion that these self help groups either replicate existing provision or intend to be a threat to the formal services. It was equally clear that the support etc. that was offered in a self help context could not easily be provided within the formal services. It was apparent that many people felt a need for something and recognised that it was not available within the existing provision. This could imply a provision gap but seemed more clearly a recognition of the value of self help and mutual aid as something that existed outwith that. It was clear that the services were unwilling and also unable to expand in that direction and that self help groups offered something that was unique, original and not replicable within the formal services. Attempts by professionals to 'run' self help groups met with varying success.

Overall, it was apparent that people sought out self help groups for needs that they did not expect to be met elsewhere - they felt isolated, uninformed, sometimes anxious, and often wished to help others 'in the same boat'. People felt that professional time was valuable and not to be wasted on what might not be strictly defined as a "real" medical problem. Their experience had shown them that medical professionals did not deal with emotional, psychological or everyday type of difficulties. People also chose to deliberately enter and continue with a mutual support relationship from which they both gave and derived benefit. It was in the groups that the psychosocial aspects of cancer were addressed.

Women who had received their health care through private or National Health Service (NHS) provision were given little information.

"From the start I had no information at all in hospital. I went as a private patient y'see. So that when I came out, I saw nobody, there was nobody in hospital. I didn't know anybody that had a mastectomy. So I felt that I was so isolated, and I didn't know what to expect." Tanya

and

"...I would have willingly gone earlier had I known that there was one (a group). But I just didn't know there was one. Because there was a lack of any communication really, with anyone. I think, if it had been V--- Hospital, or even any of the special hospitals, they do have somebody that you can contact. Who comes to tell you things, to explain things."notes: Laura

The NHS specialist units were more likely to have a nurse counsellor, a social worker or indeed a research worker, but even women treated in these centres did not get the information they wanted. The hospital (V--) mentioned above had, at that time, an apparently well co-ordinated system that included all three as well as a psychiatrist and contact with two

self help group's. But it would be true to say that that type of provision was unusual and might only occur at a high prestige city hospital or specialist unit. On a general surgical ward women were far less likely to have that sort of contact and were also more likely to suffer from the personal isolation that Kirsty (above) was talking about.

Many people felt that they were ill-informed, and they had difficulties talking to professionals, and therefore getting more information. Sometimes they found that the information they wanted was not available, or there was no one or no time to give it.

"It was quite simple things, really. I wasn't sure if I should be stretching up on the op side, or if I would always be stiff. I had been doing some gardening and my arm came up, and that was frightening, but it wasn't so bad next day, so the GP wasn't sure either. When my check up time came, it was very quick, and I felt so uptight that I couldn't remember all these things, and they seemed so trivial anyway....when I went to the group I found, well, nearly everyone I spoke to said 'yes, yes, I've had that'. What a relief! I found that they all had problems talking to their doctor, well maybe not all, but I wasn't the only one." Diane

The reason most often given for joining a self help group was to get more information and support. Most of those interviewed mentioned this in some form or another. This was important for them during diagnosis and treatment where it seemed they wanted information to help increase their psychological autonomy, to allow them to understand what was happening to them. Research has suggested that people often wanted information, but not necessarily to make clinical decisions (Cassileth et al 1980, Sutherland et al 1989). More often than not this was not available in the hospital setting, and women when they returned home found themselves wondering what had happened, and where they should look to for information.

This seemed to become most apparent to people after they returned home, and the supportive surroundings of the hospital were not readily available. The group began where the hospital ended.

"You see this group is more about the mental attitude after you get home. Ah mean, in hospital yer all right. Yer surrounded with everything, ye get everything done for ye, and yer all the same.

Its *after* ye get home, and the initial neighbour of good will and all that dries off and yer left entirely on yer own. Then, its then it really gets ye. Because ye start thinkin', ye can't lift yer arm, ye can't do this, ye can't do that, and ye start feeling very sorry for yerself. It would be very very easy y'know for people to say, ah well, that's it y'know. And just go mental practically. But, of course, ye've got to fight it. It depends on yer nature. Everybody is different." Mrs Hatton

Most people did seem to go through a readjustment time, related to getting back into everyday life after a traumatic and life changing event. It is interesting to note that studies which show immediate pre- and post- operative reductions in emotional reactions through intervention (eg Morris and Royle 1988) also indicate a levelling off of any positive effects after 4-6 months. The power and the expertise of the hospital surroundings certainly served to reassure individuals while they were there. Feeling dispirited a few months post operative was related to this and, as indicated above, to the general falling away of intensive supports. It was

interesting to note that even when women were given information about the availability of a self help group, they usually waited until they had been home for a few months before making contact. This was the case in groups with professional organisers as well as member run groups. Perhaps it was the appearance of normality, the front, that women tried to maintain that in some respects hindered others (and sometimes themselves) from recognising the full impact of the disease. To some people it was of course a valid and effective coping mechanism. People tended to forget the more hidden aspects of the shock.

K: "...but inside its so, I find so devastating that you need something to ehm, plan ahead for. To look forward to. Inside it affected me really."

S: "Mmh, So you think the group helped you with that?"

K: "Very much helped me. Because the actual, in actual fact, the first time I went, strangely enough, the thing that was bothering me, one of the big things to me, was that I couldn't find a bra that I liked." Kirsty

This was a good example of how emotional concerns were sublimated, or expressed through concerns about appearances. This occurred frequently in the groups where emotional concerns were sometimes expressed as concern with appearance.

Although there was a great deal of support to be had in the groups, it was not formalised or specifically highlighted except in the emphasis on shared experience.

"I wanted to find out how other people were coping, about clothing and swimming, and I did want confidence." Wilma

So this idea of appearance and image was tied up strongly with deeper levels of self confidence.

This "giving confidence" was a recurring feature of groups and came up frequently in breast treatment groups when discussion focussed on what the group was about. It was important that the issue of appearance and confidence as linked was not undervalued and that women were not construed as frivolous or neurotic because of an expressed concern with looks.

Some people did say that they had little or no adverse psychological effect - and indeed appeared well adjusted at the interview. Some came to the group to do "voluntary work" or more personally to help others. These people were different from those who started as volunteer workers (see chapter 5). Some women saw this as something that they could do because they felt they had a less traumatic or disturbing time than others,

"I mean I've had no psychological effect from it. But I could see that, in fact I was amazed at the number of people who had. Who were, y'know, who went to the doctors for depression and oh, all kinds of things wrong with them. And I felt well, If I can go along and say "I'm okay chums" y'know. It could be a help. Not to me, but I hoped I could give something to them. I'd be there to put into the meeting, or into the group rather than to take out..." Irma.

Certainly Irma did put a lot into the group, and also later organised other meetings on her own. She was an extremely independent and capable woman who had previously held a responsible management job and travelled to many parts of the world. It is, of course, impossible to say how much of this was denial. By all accounts she had coped with the experience, as well as two incidents of metastasis. It might seem as if the group gave her nothing, but she was clear that the group reinforced the image of herself as an active and capable woman.

Others said that they had joined the group to help,

"I joined the group with the idea of helping other people. As I say I really didn't need help myself. So I thought there must be..I had seen people in hospital just completely fall apart when they were told this. I'd seen women crying for hours on end, and mostly when their visitors came in and things like that. I thought there must be a lot of people out there needing help. That's why I joined the group."
Ethel

Ethel defined herself as being able to cope with the diagnosis and treatment. She felt that she herself did not need any help, but she did not say why that was. Having seen how affected other women were she wished to help. She did not say that she herself got any emotional support out of it, but it was apparent that she gave a great deal.

Other people said that they had gone along to the group to be helped, or to get some sort of reassurance or support.

"You are shattered, you are completely shattered when you first go. You go there looking for help. And its only someone who has been through something like that..." Clara

"I went because I thought it would help me. It (the mastectomy) was very traumatic. In that respect, yes, it helped. I made friends and kept in contact." Kirsty

"Well you do get a bit depressed when you get home. And this (the group) was to bring you out of your depression. really. And to talk of other topics other than cancer." Carol

The first woman, Clara, went immediately after she came out of hospital, "the next month really". She was unusual in this. She had sought out the information about the group from a social worker. At the first meeting that she attended, she had been quite overwhelmed and had cried for the first time in relation to the diagnosis and treatment. She subsequently played an active part in the group both in terms of its organisation and at meetings.

The second statement comes from a woman who felt herself isolated as a private patient and her motivating concern was to get in touch with others.

The depression of being home and away from the powerful environment of the hospital and coping with the reality of everyday life was something that came out as a major factor for Carol (quoted above). This was what precipitated her toward a group.

These are just three examples of women who went along seeking some form of help or support. Some people voiced the mutuality of this help but often this was not overt when talking about their reasons for going. It would be mentioned as something that they got out of the group or something that they were in the group for.

Some people had thought about their involvement in the group at length, and one woman in particular stated very clearly what had happened to her, which was by no means unusual.

"Well, I joined at first, I thought I was getting involved, sort of to help other people, to pass on your experience. To say, look, I know how awful, how awful it is for you. Because you always get a pang when you hear about somebody whose just been diagnosed. And you think "Oh god, the worst time!" Y'know. One of the worst times really. Stunned. No, I can't cope with it, and no I don't want to know. And I thought well, I can pass on my experiences and I do feel I've helped other people. Y'know like supporting them when they go through their bad times, bad check ups, take.. Oh that's something else I do sometimes, transport people to hospital for check ups and things like that. And if they really have a bad time you feel bad for them. But as time went on I realized it was helping me as well. It was strange really." Lynda

And certainly there was something quite different about unilateral helping rather than entering into a reciprocal relationship which Reissman (1976) describes as the 'helper principle'. This was seen as one of the basic underlying tenets of self help groups functioning - at least in theory.

Overall, people went along to a group looking for help and support and information. They most often went some time after they returned home, and some had an idea that they might help others as well as themselves.

EXPECTATIONS OF GROUPS

Most people went along to the group with little information about it. Prior information was as sparse in those joining professionally run groups as those joining member run groups. Many had expectations that the group might be full of stereotypical 'cancer patients'.

"And I thought that it was probably going to be a lot of grotty old women sitting around talking about their operations, y'know. (Laughs.)

So the first time I went I bullied a friend into taking me. And she said if it is a lot of grotty old women sitting around talking about their operations, we'll go home. But it wasn't, so we stayed." Chris

People anticipated group members who would be older, ill, and depressed,

"For myself - to go along, and I was so surprised to see such a varied group of people." Diane

"I was quite surprised, and I was pleasantly surprised that there were young people, and very modern dressed people (laughs) You don't think of all the people it hitting; or yourself." Pamela

and

S: "So did you expect something different from this group?"

Liza: "Yes, going on the type they were, they were they were a very cheery group."

It seemed that a stereotype existed of a slightly morbid group of older women. And although all these women themselves had had a cancer diagnosis they had not changed their stereotype of "the cancer patient" until they made contact with the group. People were aware that they were joining a self help group but they were not sure what that meant, what they might do in the group or what they might talk about. Paradoxically, some feared that the group would concentrate on cancer. They clearly did not want to sit around and discuss illness and operations per se.

"Well, at that time, ah didnae feel as if ah wanted to go into a group because ah thought awe they're goin' to talk about is, y'know, what they went through and awe the rest of it. Ah thought they wis, sort eh, awe they were goin' tae talk about." Mrs Sears

But even though this is what was expected when they went along it was seldom fulfilled in reality. But it was a reason why people delayed in going to a group, and may well be a reason why people never get along to the group at all. This might mean that many people who might have benefits from contact with a group were delaying going or did not go at all.

"Well, I just didn't. At first I can't say that I fancied the idea of going and talking about cancer and all that. And I was told, that's, there's other things to talk about, we don't sit and talk about cancer all the time. And its true, they don't. You get a good laugh sometimes-because they're such a nice lot of people." Mrs Hatton

"I didn't go for a while. I didn't want to talk about it" Deidre

"Well I really thought, y'know, that they would always be talking about ehr, yer, ehm, yer trouble. But its not like that at all. No, its really awful nice. We have keep fit the next thing." Chrissie

Talking about cancer was a prevalent expectation. For those women who knew about a group right from the assessment and treatment stage it was a reason why they delayed in going to see what the group was like. They preferred to delay till they felt that they could cope with it. Many of these women were those contacted through a professional.

This may have repercussions for who does and who does not go along to a group and at what point. These data do suggest that most people seek out a group some months after returning home, whether they know about the group or not. This may be due to the poor publicity and image the groups have, or it may be that people would chose to go along then, because it becomes relevant to them. It is not possible to answer this definitively from these data, as it requires a more controlled study focussing on presentation of the groups' image.

Many people were also uncertain about the meaning of 'self help' when they first heard about the groups. Some thought the group would be like therapy groups they had taken part in, and were unclear about the group organisation.

"With it being called a "self help group" you think, Oh God, what are they going to expect of me? And I was very, felt I wouldn't be able to do anything. I didn't know what a self help group was. I'd never been to one before. Although I had..at one stage went for day therapy, so I thought it might be something like that. And I wasn't all the that keen on it being like that. Because the type of one that I went to there were real, real deeply psychiatric cases, and I ended up doing all the helping, y'know." Kirsty

So although people perhaps feel that they might have to participate in some way, they are not sure how. Some expected to have to talk during the group, or be involved with hospitals. They were concerned to help others who were going through what they had gone through and survived.

"I don't know. I thought it was to help others, not there in the group, but before or just after an operation. I'm not sure how well it will work." Celia

"I had no idea, really. I just thought it was going to be a group. The main thing was that we could maybe help other people that still had the operation to come through. ..a self aid group really." Diane

Additionally prospective members did not know what relation the group had to formal services and professionals.

"I didn't expect so many people, actually. I was quite surprised. The first time I went there were quite a lot of a few nurses, from ehm, not Rex, but, I've forgotten the name. And there was also a GP who was interested." Heather

"I thought I would be one of the older ones. And I was pleasantly surprised when I wasn't really. When I was average. And, ehm, I don't know what I expected, I didn't expect so many social workers there, but I was pleased they were." Nora

So people were interested to find professionals involved in the group, and were not deterred by them. They, therefore did not see professional involvement as incompatible with self help. Indeed in some of the groups professionals were regularly at meetings, and this was easily accepted. In others there was little professional contact at meetings, and this, too, was accepted.

Overall, people go along to groups for a wide variety of reasons, that are predominantly social or psychological, and not overtly medical. They seldom have a clear understanding of what any group offers, and are sometimes deterred by their view of a self help group. People going to a group that is run by professionals do not seem to have a more realistic view than those who go along to member-organised groups. People tend to look for 'something' some time after they return home, and the next section examines how they access self help groups.

GOING TO A SELF HELP GROUP

For most people going along to a self help group was a decision made on the basis of remarkably little evidence and information. For this reason it is important to look at how people

came to go along to a group, both how they heard about it and what they expected of it, and how they actually decided to go along to a meeting or make contact.

This section will deal with the actual means by which individuals found out about a group, and has implications for policy. If promotion of groups is likely to be a policy objective, then the route into them needs to be less arbitrary and haphazard. It is therefore useful to identify the main means of access into groups so they can be more systematically promoted. It is also interesting to see the role that professionals played in this process.

Of the people that were interviewed it appeared that within the groups the means by which people heard about their particular group was remarkably consistent. Thus most of the women interviewed from group E heard about the group through one of the social workers in the group, while most of the women interviewed in group B came to the group via personal contact with a group member. These modes of communication did seem to highlight the underlying structure and organisation of the groups. Very few people were referred by a professional outwith the group.

There seemed to be about four main means by which people who might be potential members came to know about the existence of a group. These were through the media, through personal contact with a group member, via referral from a professional, or by seeing the groups' literature or leaflet in a public or clinical setting. Each will be dealt with in turn.

THE MEDIA

One method that was often cited in the literature as of great importance (eg Robinson and Henry 1977) was the media. There was little doubt that if a group did get some cover on the local radio or newspaper or on TV this could bring its existence to the attention of a large number of people.

The information was controlled, less by the group, than by the presenters/journalists. Information was not always wholly accurate and may have a detrimental effect, eg newspaper articles gave the wrong date for a group meeting.

The media could work in many ways to put people in contact with one another. Quite often the response to media publicity was unpredictable, ranging from a few phone calls as the result of a TV slot, to a flood of enquiries after a radio program. But on the whole those people who make contact with the group through some form of media presentation were put in touch with one individual in the group. And they could take it up from there, or not.

Fairly typical was the following story,

"I heard through the Grapevine on TV that there was going to be a radio program about people wanting to start a self help group. Missed the radio program because I was at work. Rang (the local) radio, and they gave me Mat's number, so I talked to him. And eh, we just chatted about our feelings really. How I felt, how he, how he was- and how they were similar. Then he just said would I be interested in coming to a meeting if he got one together. And I just said "Yeh". So I went to that, the first meeting was held at B--- in S---. And there were about 30, 35 people there.

And like from that it was firmly established that there was a need for something.”
Jeanette

In this particular instance Jeanette and Mat were in touch before the group got going, but the process of telephone contact and then going to a meeting was repeated throughout the study. The interesting part of this account was how they talked about their *feelings* on the phone, ie. it was not a one way interaction, but the self help mode was already evident where people shared experience etc.

There was little doubt that Mat worked hard at getting the group off the ground and presented his ideas in many forums before the first meeting actually went ahead. He did a broadcast on local radio, as well as a couple of articles in the local papers.

“We found out that my husband had cancer (said almost inaudibly) and there was an advert in the Evening News about a (self help) group. Telling what it was. So I phoned up Mat and I went to the meeting.” Ursula

So the general scheme seemed to be an initial alert via the media followed up with personal contact with an active member of the group. This often required some persistence, and on occasion telephone contact with an impersonal source.

“So I knew of nothing(to help), and then out of the blue I heard Mat on the radio! And I was really excited about this. Y’know, on local radio. Talking, saying how. he could put into words what I can’t - how I felt about this, that you need someone you can talk to. Eh. So of course I got in touch. Rang him. There was a number. I rang the local R--- (radio) for his number.” Lily.

In this instance Lily had been actively looking for something, although she was not sure what. But the group seemed to fit this need and she was a regular attender at group meetings, interrupted only by bouts of ill health.

But initiating contact sometimes required persistent effort,

“I read about it in the T--- Express (local paper). I saw this advert which said “If you’ve had cancer and would like to talk about it, eh. Get in touch with Mat B.” And I phoned several times. As always Mat is never in and I spoke to Q, and I decided I would go along to the meeting. Now at that time it was in T---. In the T--- Health Education Offices in K-- Road.” Earnest

Earnest did go along to a meeting even though he had been frustrated in his attempts to make a personal contact.

This seemed to be a viable route in to the group and people who had made contact this way felt generally comfortable with it. It seemed to be a fairly characteristic way of getting into a group F, and was not limited to that group.

“It all started when I saw an advert in the paper about a meeting at the Women’s Health shop. There I met Sonya, her sister and Bessie who said they were just there for a look and that they had their own group in D---.”Liza.

So Liza went along to one group meeting but ended up making decisions to go to another. Mainly on the basis of the personal contact with members of that group. She continued,

"Then a few months later I got a letter from (another group) saying that there was going to be a talk by Dr S about diets and things. So I went along and met Sonya again. In fact I met her outside and I said that I was a bit embarrassed and said that I had not been since last time I had seen her there. She said, "Neither have we!" and said to come out there (to D---). So I started going out there instead." Liza

Being invited back to a meeting by letter was something that only a few groups did and only on certain occasions. Mainly because of the cost groups only tended to use a mailing system when they wanted to bring attention to a particular meeting and wanted to encourage people to attend (usually when a well known local professional was speaking). Many also did not keep updates or complete addresses etc.

In some instances it was clear that the larger numbers who attended these meetings were partly to present a good public image to the (usually high status) speaker. This was something that the group used to legitimise itself (see Chapter 6).

One of the main ways of encouraging people to attend a group meeting was a presentation in the media, after that initial contact other factors operated. No-one made any particular comments on how realistic an idea they received from media presentation. News of the very existence of a group was enough for people who were ready to participate. If they were not, then they had the information available for future use, when they were able to attend. Most people in this study who had heard about the groups through some form of media presentation made almost immediate contact with the group or a potential group member.

Those groups in which members cited the media as a source of initial information about the group were those located in the cities and who covered a wide geographical area. They tended also to be those groups that included a wide membership. To get into a group in that way required some action by the potential participant. Although the information might come out of the blue, they had to follow it up themselves, in the first instance, with no encouragement from anyone involved with the group, and with very little information.

Those groups that were run by professionals were the least likely to make use of the media as a means of access to the group.

PERSONAL CONTACT

Another, fairly common, way of getting into the group was through a personal contact with a group member, or someone who was a close friend of a member. Again this seemed to be related to the geographical and community location of the group. The group for whom this was the dominant mode of entry was group B, a small, closely knit group which essentially reflected the community from which it came.

"When we moved here Lynda was talking about it (cancer) and Ah told her Ah'd been in for a mastectomy. And she said she was trying to get a wee group up. So Ah said Ah'd be willing to join it. Ah think it had maybe been going for a couple of weeks before that. They were in at the Western (Hospital) first and then they gave it up because they felt they weren't getting anything from it." Mrs Farquar

So a 'casual' talk led to a discussion about the group and another member was found. This group did have a high profile in the community and seemed to be known to exist by most people in that area.

It was certainly the policy of this particular group to visit people in the area who had been in hospital. This was usually done by a group member.

D: "Lynda found out that I had had a mastectomy and she came down to see me when I came home from hospital."

S: "Had you known her before then?"

D: "Well, as a neighbour, y'know just..because I've only been here five years y'see. they've all been here for, yes yes. So she came to see me and told me that there was this group, and when I felt like, or if I felt like coming, then just to let her know." Deidre

Even on one occasion someone was visited before they went into hospital

"They heard about me being ill even before.. Ethel was down to see me two days before I went into the hospital. She had an idea what was wrong with me." Mrs Norton

And certainly this caring community attitude was prevalent also at group meetings and the group members acted in a reciprocal caring way.

"At first I was "Oh I don't think I want to start going to this meeting" but eh, I got, eventually somebody got me to go, and I'm quite happy." Mrs Norton

"...June W, round the corner (got me to go). Well it was through them that she was helping me. It was a case of "You keep your eye on Mrs Unsworth (herself), you help Mrs Unsworth" and I feel well, if they are good enough to do what they have done for me, its up to me to go really." Mrs Unsworth

This practical every day helping seemed to be a major feature of this group and something that tied the members to it, and encouraged people to go along.

"Lynda and Jim came down to see me, then they got me to start coping and I was able to go about. And that's how I started.. I knew about the group before. I didn't have a great deal to do, I had nothing much to do with it. But I did know. And Sadie started going after her husband died." Ailsa

Although this was highly characteristic of this group, they certainly were not the only group to operate in this way. In fact there was no one group in which someone did not indicate that they had heard about the group through personal contact. But in no other group was it so persistently and characteristically done by group members. Although it did happen that people in the professionally run groups made contact in this way, their interest in the group was usually mentioned to the professional before the new member attended, or else they were

advised to contact the professional themselves. In group E this was followed quite closely, but in group C people seemed to feel quite free to bring new members along to the group and take responsibility for that.

In most groups this type of contact was fairly haphazard, and chance played a larger part. For example, it might be important who was in the next bed in the hospital.

"She (the woman in the next bed at the time of mastectomy) was involved in the formation of the group that's how I joined it. Now, with me keeping in touch with her, when I felt able to go to the group, that's how I joined it. So I joined in the first year of the group, as it was just getting going. But I wasn't there in the formation, but the girl in the next bed was." Celia

This apparent chance contact was maintained and served, amongst other things, as a link into the group. This maintenance of relationships was not unusual at all as many women said that they had kept in touch with other women who had been on the ward. It seemed that patients would talk with each other and would keep up their relationships sometimes through a group or by personal contact with each other. Often the women interviewed kept in touch with several women through check up visits to hospital.

The individual contact served the purpose of occasional support and comradeship. It also seemed a forum for exchange of information, comparing progress etc. Perhaps this is the basis of medical fears about groups and their independence and their "deviant" knowledge. This is an area that requires more attention, but was outwith the current study.

Sometimes people met in other organisations

"I belong to a small non-violent direct action group and one of the members belongs to the same church as Sarah. So when she knew I had breast cancer...she said I'll put you in touch with Sarah K. Well, then, in between treatments, I think, I was at the vigil one day and met Nina and Sarah. They were there and said, come along if you want to." Kathy

This highlighted one aspect of making contact through another person - that people were open about having had cancer. Quite often people were concerned about disclosing this to a general audience. So any personal introduction to the group must be based on knowledge of the health status of others. The use of the media did not require this, as only that individual takes the initiative and makes the contact, phones up the number or whatever. It was generally recognised that this might be a difficult thing to do, feeling fragile and not particularly confident. On the other hand for anyone to make personal moves to introduce somebody to a group focuses attention on confidentiality and there is a possibility of intrusion. It was not too much of a difficulty where an individual knew a friend in a group. It was certainly recognised and carefully considered in those groups where people were visited at home as an introduction to the group.

It was quite a different matter where it was a group member visiting or where it was a medical professional involved in the group that made this initial visit.

PROFESSIONAL REFERRAL

When this thesis was originally envisaged it was thought that professional referral to groups would be more common than it proved to be. Groups did not exist in isolation from medical professionals, nor did they wish to do so on the whole (even if they could). Given the importance and frequent contact of professionals to group members it is significant that so few people were encouraged by professionals to try a self help group as a means of support. The professionals interviewed in this work did have some contact with and knowledge of self help, and had recognised the psychosocial aspects of cancer remained reluctant referrers. The data suggest that group members sometimes used their individual contact with professionals to publicise their group, and would, for example, mention it to their general practitioner or consultant. This was also a legitimisation technique, and is discussed more fully in chapter 7.

There could be several reasons for the apparent lack of professional referral into these groups. There may have been people referred to the group by professionals but they had subsequently left and were therefore not part of this study. This might indicate that the group did not serve their needs, that they had been "wrongly" referred, or had been correctly referred and obtained what they wanted and left. Perhaps there had not been many people referred to the groups at all. There were strong indications from these data that professionals had an unrealistic idea of what a self help group was about. Few people were referred to a self help group by a professional who was not closely involved in the group. However these data cannot fully address the issue, but can document the small number of cases where professionals participate in the entry into the group.

Issues raised in the previous section concerning privacy and intrusion of visiting people at home was of particular importance where a professional was involved. In one group (C) it was often the case that women came to know about the group through a home visit by the group's main organiser. Frances (the specialist nurse) had set up the group to allow women to gain benefit from being together, and also to help her stay in touch with an increasing number of women. At the time that the group started it was seen as part of her job to visit women at home in the area who had been treated for breast cancer.

Once the group was set up she would mention it the first time she visited women when they came out of hospital and encouraged women to go along when they felt able. She herself maintained some sort of supportive contact with individuals.

"Mrs F (specialist nurse) she came to see me like, after ah came out of the hospital and that. And she explained to me that they had a group -and asked me if I would like to come along.

Well at that time I didn't feel as if, I sort of wanted tae go into a group - because I thought oh, they're going to be talking about is y'know what they went through and all the rest of it, y'know. I thought that was going to be all that they were sort of going to talk about." Mrs Sears

In the course of the general visit then, the community specialist nurse (CSN) would mention the group. From this account it seemed that she did not exert any pressure on women to attend but let them come, if they were going to, in their own time. But it was also apparent that Mrs Sears had an idea and expectation of the group that was not fulfilled in practise. Where this expectation arose was a matter of concern. It would seem unlikely that Frances (CSN) presented the group as something that it was not, and one can only assume that there was a general idea of what a self help group of this sort was like. It was quite a pervasive stereotype as will be shown later.

Quite often the recruitment of women into the group was initiated by Frances but during the time of the fieldwork the practise changed. Women would only be visited and told about the group etc. if they said they wanted this in the hospital (a specialist breast treatment unit with a nurse specialist). So a system was set up where the hospital nurse specialist would inform Frances (CSN) of any women who had shown an interest in being visited at home. A fair portion of women took up this option, but by no means all.

This policy seemed to come about as a result of two considerations. One was the increasing work load that the community nurse was carrying, because as more women in the area were identified as having cancer over the years the total known to her increased. Also the dissemination effect that had been hoped for via the group had not been effective to the extent that had been anticipated. But there was also a recognition that "the patient must have a say". This meant that women could maintain some degree of control over whether or not they got a home visit. It also meant that Frances knew she would be expected when she made contact. An issue that had bothered her throughout.

As far as encouragement into the group was concerned, women would not necessarily go to the group immediately (for a variety of reasons) but would put it off for a while. Women sought out the group some time after they went home when they had to face the "real life" problems again. Members of the group were aware of this, both in themselves and in other women, and made allowance for it. It was not unusual to find that after the initial visit by the specialist community nurse one of the group members might phone up a woman and and re-introduce the idea of going to a meeting.

"Mrs F (Frances) she sent me a tape, of people that's had the mastectomy, y'know. To cope with what happens. And she's involved with the meetings as you know. So she actually (visited) and Sonya telephoned me and asked me if I would like to go to their meetings. Which I did do. And I've now been going over a year."
Regina

Few women speculated as to how the nurse had their name in the first place and seemed to see it as the mysterious way in which the medical system (or bureaucracy) ran.

"I think through Dr McL--, Dr N McL--, who was the lady doctor I saw to start with. Eh, she must have passed on the message to Mrs F. who was really very kind. Telephoned me, and tried to reassure you, and they did have this (self help) group." Chris

So women who heard about the group in this way did seem to see it as, if not an integral part of the local medical set up, at least as comfortably linked to it. This could have had repercussions for who did and who did not join the group. It's difficult to ascertain from these data, except in the way that women in this group in particular used it as a forum to validate symptoms for presentation to another professional mainly through the nurse, eg showing to her swellings, or lumps etc that they were concerned about.

Important distinctions could be made for those women who found out through the media and those who were visited by a professional person. Primarily those in the former group took it upon themselves to find out about the group and to go along, while those in the latter situation had the information presented to them - they did not have to seek it out. This may have resulted in quite a different view of group participation and certainly seemed to have made a difference to the perception of the group and its relation to professionals. There is no criticism of either method implied here, but they are different and may have different effects and might 'catch' a different population.

One other route into the group was explicitly managed by professionals. In the particular instance of group E, a social worker, who 'covered' the breast treatment ward would mention the group or, as in the breast treatment unit in Edinburgh, two hospitals' leaflets telling about local groups would be included in a package that was given to most women on the ward. Interestingly none of the people interviewed had come into the group by the latter means. Possibly the leaflets were not available at the time they had surgery, or in that particular hospital.

In group E, most of the women had come to hear about the group through a social worker,

"There were two social workers attached to the unit. Jean and Mary. I'd said during the clinic it would be a good idea if we all got together. They said they were doing something that was much along those lines." Nora

The social worker seemed to liaise quite well about this and women from surrounding general hospital might also hear about the group through this channel.

"I heard about it through the social worker at the hospital. I was at W--- hospital and there is absolutely no after care for cases like mine. Whereas in V--- hospital there is a marvellous aftercare service...and one of the little Housemen at W--- was an absolute poppet really. He got the social worker to come up and see me and she spent half an hour talking to me and she gave me all the gen I didn't know of the existence of the group. She gave me the leaflets and details and what-have-you." Clara

So in this Manchester group it was very common for a social worker already involved in a group to refer a person to the group, and there was also a lot of social work input into the other group there too. This was seldom the case in Edinburgh, and may represent a difference between the two cities in the policy of the hospital social workers.

Sometimes social workers acted as a liaison between people with similar interests and was instrumental in encouraging a group to set up (in this case group F).

"In 1980 Mrs B--- (principle social worker at C---) put him (husband) in touch with Mat. And she said that this bloke had also been in touch with her and wanted to start a self help group similar to what Thomas had in mind. So Mat wrote to Thomas and we met Mat." Ursula

And although the two men felt that their ideas were a bit different they were at least brought into contact. Unfortunately Thomas died before the group was eventually set up by Mat. However Ursula, the narrator, continued her involvement in cancer self help and played quite an active part in the group.

Other health professionals also acted as a liaison. A further example of this was in Edinburgh where one attempt had been made to try and set up a group and it had floundered. A second initiative was started, and all the women who had shown interest in the original attempt were contacted by the specialist nurse.

"...because what they did, was that they got a list of people who had been involved in the first group. Eh, because I think that NB (Nurse Counsellor) must have had that. And sent letters out, and, or, called up to ask if we would be interested in coming to a meeting of a mastectomy association. As they still had the list from 1979 with all the women who had shown interest at that time, and that's how they got that amount of people." Pamela

So it is clear from this the liaising that a professional person was likely to carry out in that sort of situation, ie by maintaining records that were passed on with the post.

In other ways people who were seen as coming under the medical umbrella could act as enablers to get people together in an organised or formal way (there was no doubt that "patients" got together anyway). In essence their action in this respect was little different from a friend suggesting a group, but that action had a different interpretation. A nurse counsellor may suggest a group as an option,

"She gave me Sarah's address and phone number and I phoned up Sarah and had a chat with her. And I can't remember whether she came down to see me or whether I went to the meeting first of all. I just can't remember." Berthe

Once again it seemed that the personal contact was important, and also that people did not always clearly recall how they got into the group. This was a fairly rare occurrence. People were mostly clear about the events that lead them to it, but recalled less accurately the timing of those events. (Berthe had metastatic cancer at the time of the interview, and died shortly after.)

It was clear that she had been having problems and derived great benefit from her involvement in the group.

"And of course there was no help available for people who had just had mastectomies. Our own doctor would do nothing. Nobody seemed to be able to help at all. And I was really down.

However NB (nurse counsellor) came down to see me and from then onwards I seemed to pick up and y'know realize life wasn't over. I still had something to do - and I went on from there." Berthe

In all the interviews there were few other instances of a referral into the group from anyone who was not closely involved in the groups. One such was by a clinical psychologist who "encouraged" a woman who had been referred to him to go along to a group. He had been along to the group and given a talk and then maintained a regular spot in the program.

"He actually had the program with him and he rang up to say I would be coming. Because I was at the stage where I don't think I could have gone on my own.

So, because I knew that they knew that I was coming I would go. And I actually went to the meeting that he said that I would be going to. And that's how I became involved in it really." Kirsty

Whether this could be called being pushed in to a group is debatable, what remains without question was the benefit that Kirsty derived from the group and the group from her.

No-one else who was interviewed had been professionally referred into the group. During the field time, however, one group received professional referrals, and another was approached by social workers with a query about financial assistance for patients. The former came to group D, who, amongst other things, supported group members through severe illness episodes and helped cope with death and dying. They were asked to see a woman in the terminal stage of her illness. She died less than a week later, but two of the group members had visited her, and her relatives during that time. The group felt that they had to respond to the personal needs of that woman but realised that the referral was inappropriate. It had been requested by a GP who appeared to have no clear idea of the group. Although the group tried to move the referral onto a more appropriate service (Macmillan nurse), they felt that the woman benefitted from contact at home from group members. Indeed this was emphasised when the relatives showed their appreciation.

The other referrals mentioned were similarly inappropriate, being people in the latest stages of illness and rapidly approaching death. In all instances each group did what it could, feeling that they could not refuse if they might help, but also that there was little else available. Referrers had not made the distinction between the group helping its longer term members to approach death and stepping in at a terminal stage with a bereavement service.

The reason why doctors and consultants didn't, on the whole, mention a self help group to someone distressed by a cancer diagnosis remained a pertinent question. It may be that they were not convinced about involvement in a group. This was, however, not the main view forwarded in the interviews with professionals carried out in this study. They did see the groups as benefitting some people, but they were also aware that the groups operated outwith their control and outwith a professional system. They could not be held to account in the usual (professional) way. A self help group by its very existence was perhaps threatening to them,

regardless of what it did or what its members were seen to do. They were not actively encouraging women into the group, but also did not appear to discourage attendance.

Those professionals who were actually involved in the group were in a better position to make contact with potential members than group members themselves. There were, however, no more members in those groups than in the others. This suggests that maybe the groups were as efficient at publicising themselves as professionals, or that people who are interested in this type of support seek it out regardless.

LEAFLETS

Medical professionals helped by having group literature in the clinic etc. Sometimes the leaflet of a local group was included in the package that women got when they were on the ward.

"I first heard in hospital. They gave me this leaflet telling me the dates and I was welcome to go along.

And the first thing I saw (in the leaflet) was Dr B--- who is a personal friend. And I just missed him because he was the sixth of March and I wasn't well enough to go out then." Nora

This woman had got the information at the time of initial treatment and decided to go along quite quickly afterwards. To contemplate going so soon was quite unusual - most people went several months after initial treatment.

People maybe saw the leaflets several times before they decided to take it up as an option.

"And while I was there (at C--- hospital for further treatment) I saw the little notice, the sort of leaflet. Anyway I didn't do anything about it, I only read it. I never rang anybody or contacted anybody. And then there was, ehm, I had to go for my radiotherapy in May, and I was in C--- for three weeks. And eh, I saw the leaflet again, and I still didn't do anything." Ailsa

Mary did eventually go to a group meeting in October. She indicated that she was in town for other reasons and decided to find the meeting place. But what was clear from this, and Mary was not unusual in this, was that several opportunities had occurred for her to get information about, or make contact with a group, before a decision was made to go along.

Sometimes a combination of things would bring a group to the attention of an individual, as is shown here.

"I can't really remember (how I got information about the group). I don't think that I got a leaflet at L (breast treatment unit). I've looked for it since and can't find it. I didn't know about all that at the time.

I saw the leaflet in the clinic when I went for a check up (at L) but they didn't have one to take away. I mean they only had the one.

I had seen the article in the Scotsman last year and that reminded me. I had never felt the need to go to a group for my own sake." Annette

From the interviews and from general conversations with people in meetings and from occasions that it arose in the group as an issue, it was clear that people came into the group by a variety of routes.

Where people had access to written information they could keep this until they felt ready to go to the group. The leaflets were fairly important in this respect. Perhaps their location in a clinical setting gave the group extra credence, but the action, as in hearing about the group through the media, had to come from the individual concerned. No-one else was involved.

OTHER ROUTES

Of the many possible other ways into the group, one in particular still bears mentioning. This was where "volunteers" in the group gradually came to participate in the group. This happened mainly in two groups, and seldom in the others. One of the groups recognised this process and turned it to their advantage. There were occasions when people became interested in the group as a "volunteer" rather than as a group "participant" and the distinction became blurred. Often people would be drawn into the group and become an integral part of it as the following example shows.

In group D organised volunteer drivers helped members to and from meetings. This was essential for some people who found travelling by public transport difficult. Various ways of organising a transport system had been tried and the most satisfactory was this system of volunteer drivers. Partly because of the length of the meetings and partly because of the developing relationship between driver and passenger(s) many "volunteers" ended joining in on the meetings and being integrated. At one group meeting Michael who had started coming to the group in this way told me,

"Well, I saw the notice on the board in the Western (hospital), I work in the Western. Anyway I saw this notice asking for people to drive for this (self help) group and I thought it was interesting so I got in contact. But it was really her (Nodding towards and smiling at a woman in the group who was listening) that made me come along. She just said so many things that made me think and I wondered really what they were up to in this group here." Notes: Michael

It is difficult to transfer the happy and relaxed way in which this was said. It was apparent that a good friendship had developed between these two people and been extended into the group. Although the volunteers did not have cancer, they were welcomed into the group as someone involved with a group member in a similar way that relatives became involved.

SUMMARY

In summary, it seems that there were potentially as many roads into a self help group as there were individuals. Those outlined here were the main routes apparent in these data. It can be assumed that this is by no means an exhaustive list. What was very interesting was the consistency within groups as to the mode of primary contact. Some of the stories about how

people got to know about a group were essentially also stories about how the group got set up, so those people came into the group in a unique way.

There was, however, no reason to believe that the groups radically changed their channels of communication very much in the progress of time. Rather it seemed that these channels were determined by the local area and the communication facilities that were available, as well as the way that the group was set up and organised. This was particularly pertinent for those groups where professional people played a larger part.

CONCLUSION

This chapter has examined why people look for a group. Some of those interviewed were not quite clear what had motivated them. Many mentioned a general feeling of being isolated, without support or access to information. Although this was something that had bothered them during treatment it was particularly intense a few months after returning home when everyday reality had to be dealt with. They realised that support was not available in the formal services, it was difficult to speak to professionals, and they sought support through contact with others. Although people were poorly informed about groups, they took the risk of challenging their own stereotype of the cancer patient. Some people had initially gone to the group in order to help others, feeling that they had dealt with the worst part themselves, and were in a position to support someone else through it. Many of these people eventually came to realise that the help they were giving was also a help to them. Mutual aid or self help therefore emerged in the group.

There seemed to be no clear differences between groups in terms of member's expectations. Most people went to particular groups because of geographical proximity. Where people had changed from one group to another this was determined primarily by access.

These data suggest that there were four main ways that people made contact with the self help groups. Information might be available through the media, and contact made with a key member. This required that the potential participant take their own action in finding out about the group, and might be the first public acknowledgement of cancer. Where information came through personal contact with a group, the potential member had an ally, and had made some public acknowledgement of the disease. Where referral occurred through a professional, this was observed to be almost exclusively through the professionals working 'inside' the group. Again, the potential member was in contact with someone already in the group. In one group the members themselves were as likely to have made contact with the potential member as the professional. Leaflets, giving information about the group required that the person make the decision and contact on their own, with only that to help.

Each of these areas could be explored further in future research. These data suggest that in each group most members had come through one predominant route. This seemed to be determined by geographical location, and contact with professionals. In large cities, with a

wide catchment area the media was extensively used. In smaller, local groups, personal contact predominated. All the groups had some members whose first information came from leaflets. Few professionals outwith the groups made recommendations that people try them and there was no less confusion about what to expect in a group where professionals did have an organisational role.

So, it seems that getting information about a self help group is not easy, and potential members face attending a self help group meeting with some trepidation.

CHAPTER 5 : BEING IN A SELF HELP GROUP

MEETINGS AND FIRST CONTACTS

Some interesting issues emerged in the course of discussion about the first group meeting members had attended. Most important was that a large number of those people interviewed had been members of the group since its onset. Thus the question of their first attendance at a group meeting also coincided with their own views and ideas of how the group first began and, because they were usually the ones determining what happened, the form that it took. In being asked about the first meeting of the group, many people interpreted this to mean the first meeting of the group rather than their own first meeting. For some both of these events coincided.

In terms of overall policy, if these groups were to be encouraged, it is essential to highlight what was and was not good practice in encouraging people to attend them. On a more local level, the groups themselves were concerned about their own recruitment of members and how people were brought into the group. The professionals in the groups were also concerned about appropriate recruitment of members. There were some differences between those groups with high professionals involvement and those without.

During the time of the field work the actions and ideas of individual groups about first time attenders were in some cases changed or modified as a result of direct feedback by members. These included allocating specific individuals to 'look after' new members, setting aside particular meetings for new members etc.

The choice of the first attendance at a group meeting proved to be important methodologically since it allowed a common focus on a specific time period that was seldom more than three years previous. It provided a pivot, both in terms of actual time and subjective time for the progression of the interview. Thus it conveniently allowed movement back, towards the time of diagnosis, and forward to the present. For each person the time since joining was different, from months to years. Most remembered this occasion fairly clearly, and gave detailed and coherent accounts, including one woman with metastatic cancer and a related brain tumour.

Over half of those interviewed recalled being at the first meeting where the group was being organised. Others attended meetings where the main emphasis was on a social event or informal contact, or where there was some sort of group activity (eg bring-a-bra), or when speakers were invited in from outside. This seemed to be the case whether the group was professionally or participant run.

Although the responses as a whole divided in this way, there were differences between groups which will be highlighted. The section will conclude with the action that groups took in response to feedback from members about their first contacts.

THE FIRST GROUP MEETING

It is important to look at how the groups started and how the people involved at that time saw the group and their attendance in it as well as the potential or real role the professionals might play. The beginning of a group was a crucial point when group policy was formulated although not necessarily articulated. Of all the people interviewed a large proportion had been involved in the group from the beginning.

"I went to the first meeting that was held in the Belgrade in S---. And there were 30, 35 people there and from that it was firmly established that there was a need for something. Like, there was some professional people there, but most of the people had, like, personal experience of cancer." Jeanette

The people for whom this was a first attendance had responded usually to some sort of publicity, and all of them had had some personal contact (usually by telephone) with at least one of the people who were to be at the initial meeting. Thus they had been active in seeking out a group, and willing to go along to one that was not well established.

Although the reports of what happened at that meeting vary, people were glad that contact had been made, that was the primary objective for them as individuals. Many made comments like - "I was very excited about it", and "I was glad to have even gone to that one meeting". One woman even said "I got more out of that one meeting than I had in 15 years."

Few people related in any detail what went on at the meeting, except to say that they had talked to a lot of different people and that there had been attempts made to say what was wanted out of the group and the next meeting had been organised.

"And it was just an open meeting, and we were all saying these things, like what we wanted out of the group, But really it was people saying such similar things about their family and the hospital and all" Vivienne

"..nothing was really *done* that night, except to say we would like to meet again, and Mat took our names and addresses. And then he sent out a letter saying that there would be another meeting." Diane

So the emphasis was on the contact that people had with one another and the desire to keep that going, with usually one or two people taking on some responsibility. There was no doubt that even at these initial meetings people did begin to adopt positions that they would subsequently maintain within the group structure. Quite often it was clear who was the leader of the group, because apart from anything else the initial meeting required that someone did a lot of organising.

It was often at these first meetings that people got pulled into the organisation of the group, sometimes against their better judgement.

"I went to the first meeting at C--- and I was just sitting there in the audience and I recognised (nurse counsellor). And Vivienne was saying they needed to get a committee. And I was just there to view and (nurse counsellor) said, "I nominate Lena"... I had no intention of getting involved. I knew what it was going to entail. And as Vivienne says, you have to be 100% committed." Lena

Lena maintained her position as a committee member for over two years. It is interesting to note that it was the nurse counsellor, who knew Lena, facilitated (or pushed) her into the position. There were several organisational difficulties within this group that rose from a too dominant leadership. What was important at that point was that although Lena did not want the position on the committee she was not dissuaded from going to the group, and became an active member. Thus the professional input here was welcome and helped address some of the problems of the dynamic of the group.

So, it seemed that a portion of people who went along to the initial meeting of the group were likely to remain with the group for some time, with some adopting organisational positions. It was impossible to find out how many went along to the initial meeting and then never went again. At one group which started very near the time this research began, it seemed that at least half of the early attenders could still be described as "members" a year later.

In all the groups, with one exception, at least one person was interviewed who had been in the group from the beginning. In four of the groups many of these individuals could be described as key members. In the fifth group, one person played a high profile role in the meetings, but she was not in a formal organisational position. She kept herself very firmly out of that. Both the group (E) that she was involved in and the other group (C) in which no-one was interviewed who had been an initial member were breast treatment groups. Both had more day to day professional input than any other group. In fact they were both more or less initiated and organised by professional people, and both included regular contact with a specialist nurse, who worked in the area of breast cancer. It may be that people do not stay so long in professionally run groups, either because they get less out of it in the long run, or are more able to leave.

Certainly people who were involved in non-professional groups at the beginning tended to stay in the group for some time, and to present themselves for interview. In groups where there was a high professional organisational input, it appeared that the members themselves become less involved in the group activities, for whatever reason, and were also less likely to stay.

The question arises as to whether in fact members do become less involved because there are professional people there, and it is suggested that this was sometimes the case. There were fewer roles that members could play if, even inadvertently, professionals 'professionalised' those activities. This indicates that participation of professionals in self help groups may not be an easy task, and is commented on further in chapter 7.

It is unclear whether actual activity (ie participation) does mean that people will stay in the group. It might be the case that having a professional taking up the position of a mainstay in the group meant that people could leave the group more easily and so did not become trapped in it. To stay in a group over long is no indication of "success".

The highest number of initial attenders (ie those who attended the first or one of the first meetings) was to be found in group F, where slightly over twice as many people fell into this category than into any other. This reflected not only the large number of people who attended the first meeting and subsequently stayed on in the group, but also the number of people generally involved in the organisation and running of the group. As a whole it was very egalitarian, and participation was encouraged at all levels, so that most people in the group 'did' something.

This group did not differ markedly from other groups in terms of the time it had been in existence. It was, however clearly organised, with professional input both in training and back-up of members, but not in its organisation. From these data it is only possible to speculate that they offered a good model for a group, with a reasonable balance of active and less active participation of members with defined and limited input from professionals.

In the next part of this chapter, people's experience of their first contact with the group is examined for each of the types of meetings attended. Some types of meeting seemed easier for new members, and the group members reflected on their own personal experiences of their first contact to facilitate this for future members. This provides a good example of the self-determination of the groups, and their ability to adapt to their own feedback.

SOCIAL MEETINGS

Social meetings are meetings where the main emphasis was on personal social contact, ie there was no speaker or arranged topic. This seemed to provide an effective format to encourage new members.

There were always members from each group who had first attended a meeting that was social. The spread across the groups seems to be more or less equal, with the exception of group E. In that group very few people seemed to have attended a social meeting for the first contact. The group did have social meetings, but they were not frequent. If a group never had a social evening, then it would be impossible for someone to attend one. All the groups had "social" meetings as defined above, but they occurred more frequently or regularly in some groups than others.

Thus, for example, group F made every third meeting a primarily social or contact event, whereas group A, during the time of the fieldwork, only had a couple of such meetings specifically organised. (Although they changed their format in due course.)

Given this, it was interesting that so many people who had initially attended a social meeting, usually at random, continued in the group. During the time of the study some of the groups did develop their own policies towards newcomers, but as all the people interviewed were already attending the group before this time, this would be of importance for future members. The one exception to this was group D, who even in the first instance had a well

worked out and clearly defined system of group meetings that highlighted certain ones (social) as those for new members.

"Usually what happens is that a new person goes along to a social gathering, y'know, Saturday afternoons. Just tea and talk, y'know. And I went to one I think in February of '84, I think that's right. So, then, since then, I've been a regular member." Miriam

So this group had a particular meeting where new members were introduced and the group introduced to them. It seemed to work very well, and was a policy that was based on the experiences of the people in the group. Nearly all its members who were interviewed had entered the group in this way, with a few exceptions who had turned up at an ordinary evening meeting.

None of the other groups had such a policy at the beginning of the field work. In those groups where potential members were likely to make contact with a group member before arriving at a meeting there seemed to be a general policy to steer people towards a more social meeting.

Most people who made their first contact through a social meeting seemed to find it a positive experience.

"Well, Ah didnae know Lynda whose house its held in. And she made us, me, very welcome. Then another lady joined us who had lost her husband. So we have that, other people as well, who have experienced, eh, well, cancer in other people. Their husbands and wives and things, y'know. But, ehm, it helped.

And they did come round to speaking. Because Ah was the most recent. Because they'd all had theirs done a while ago (ie. mastectomy). Ah was the newest member of the group. So, Ah suppose we all felt, well, we're in the same boat." Mrs Farquar

So Mrs Farquar was made to feel very quickly a member of the group, and also someone who had something special to offer, her own recent experience. She obviously has some feeling of solidarity with the other women in the group right from the beginning.

In that case the organisation of the group was such that she was specifically encouraged to attend that particular meeting. For other women it was a bit more haphazard as to which meeting they might land in. One young woman told me,

"I got in about half an hour before the meeting finished, and, anyway, you know how they all go all the way around the group and asking. Well, they'd nearly, just nearly completed that, ehm, going round the group, and I'd just walked in y'know. And went and sat down, next to Mat. And then it just came to me, and I said "I've just come to see what its like. Now I've been there on four occasions...and I found it very good to be able to talk about it." Irma

For Irma then, the initial experience of the group, and the introduction of each person of themselves was fine for her. In a similar situation other people have not been so happy.

"..that was a bit...if I hadn't been used to standing up, or sitting down, and talking it would have perhaps chased me away. Its quite a difficult thing suddenly to do, but that was just the one that I happened to turn up at." Notes: Janice

Janice had taken steps to ensure that new members were not placed in a similar position.

Given that all the groups have social meetings of some sort or another and that a fair portion of those interviewed had entered the group through a social meeting it might be concluded that social meetings served as a good introduction to the group. People who came initially to social meetings continued to come to other meetings. They go along to groups because they want to have contact with other people in similar circumstances.

This was true for all but one of the groups, group E, which was set up by professionals and no-one entered the group in this way. This group very seldom had a meeting that was primarily social. The meetings followed an organised program, which incorporated, amongst those things also common to other groups, a specific type of meeting that was designed to get women to interact, but focussing on a topic or issue. This required some sort of direct participation by the women in the group, and this type of meeting was commonly cited by women as their first contact. Perhaps it provided a similar milieu as the social meetings in other groups. From the numbers of women who had used it as a means of first contact, it seemed roughly on a par to a social meeting in other groups in terms of its acceptability to new members.

The importance of this lay in the attempts made to keep control of the interactions of the women in this particular group. It was something noted in a previous report (Fiona Poland 1984). The professional workers in the group did attempt to keep women away from what they felt were 'dangerous' topics (which of course the women discussed at great length over the washing up, or during tea). This interaction was not regarded as "safe" for general discussion. Thus it would be very difficult for someone to enter this group through a social meeting, as previously defined, and get immediate personal contact.

It seems, from the above analysis, that apart from members who came into the group at its inception, the people who were most likely to still be in a group were those who first of all came to a social meeting whether the group was professionally organised or not. This supports the notion that people came along to a self help group to meet and talk to others who were in a similar position which is worthwhile noting in terms of facilitation and recruitment.

ACTIVITY MEETINGS

Many women, in the breast treatment groups in particular, had initially gone to a meeting that involved some sort of active participation by the group members. The possible reasoning for this has already been touched upon in the previous section.

It was not by chance that the two groups where this sort of activity was most common were those that had a high input from a nurse with specialization in the area of breast cancer (groups C and E). In one of the groups (E) two social workers organised the group and there was regular input from a specialist nurse too.

In that group (E), all but two of the women interviewed first went to an initial meeting of discussion on implants, a display and discussion on prosthesis or a 'bring-a-bra' session. What distinguished these sort of meetings from others in that group and in other groups was that it was deliberately organised to encourage women to talk in an open forum about their own prosthesis, implant etc. There was no doubt that the aim of this type of meeting was not only to inform women by their participation but also to some extent to maintain this within acceptable limits.

In the other group where this type of meeting was cited as a common means of first entry, this controlling element was less apparent. Indeed the controlling came much more from the active members of the group than a professional.

This type of meeting did encourage women to interact and to share their experiences and ways of solving problems. And because of the professional presence this would be delimited to bounds that were acceptable, by even the most cautious.

Sometimes it did coincide with a direct query that the first time attender had, eg.

"In actual fact, the first time I went, strangely enough the thing that was bothering me was, one of the big things to me was I couldn't find a bra that I liked. Because they throw these mastectomy bras at you -and they're just hideous. I just ooh (shudders) God, if you've got to wear them?"

And the actual night I went was, they'd all been asked to bring in bras of their own that they'd found good. And on this pile of bras was those two bras that really, I thought 'gosh - they're nice'. They're the sort I might have worn before."
Kirsty

This led Kirsty on to meet the woman who owned the bras who subsequently sent off for two for her. So the activity included Kirsty in a personal contact with a focal point that might have been less easy at a purely social meeting.

Also Kirsty got not only information but was actively involved - and she did get the bras. She continued,

"And they're lovely. I've got one on today still. And I've found them absolutely great. And that. I came home and for the first time I felt, uplifted. (laughs) I know we're talking about bras but that's how I felt. I actually did.

Plus I was really excited over those bras. And, oh it sort of broke the ice for me with the meeting." Kirsty

So it was a total success for Kirsty. This had taken place two years before and she was at a point where she was thinking about leaving the group. But it was apparent that the first meeting for her fulfilled many functions.

The activity meetings in group C also included some activities that were not directly related to breast disease. The main focus of the activity meetings in that group seemed to be primarily social rather than informative. The group tended to focus on clothing, eg fashion

shows. They all felt this was something very important for them but they were also using the skills inherent in the group members, two of whom were excellent dressmakers, and provided invaluable expertise. Thus the group was shaped by the members.

This group also included such things as flower arranging and keep fit on their program. One woman had gone along to the keep fit as her first meeting.

"Ah think the keep fit was the first night Ah went. And it wis great. Ah had a great laugh, and thoroughly enjoyed it. And everybody's that friendly - which makes an awfae difference." Geraldine

It seems therefore that the emphasis was on the contact with other women rather than the quality or quantity of information about cancer, surgery or other medical issues.

The activity meetings seemed to provide a similar function for the group members as social meetings. They were mainly about informal contact between members. This seemed to make it easier for new members who, apparently, were more likely to remain in the group thereafter. Some activity meetings which focused on cancer related topics (prosthesis etc) facilitated discussion around those issues. Other activities (eg keep fit) had no such focus, but facilitated personal contact. Those groups where this sort of meeting was likely to be the first point of contact for new members were essentially organised by professionals. Interestingly few people in other groups entered via an activity meeting. This is an interesting influence of professionals in the groups.

MEETINGS WITH SPEAKERS

All the groups regularly invited people in to speak to the group. This was usually, but not always, on a cancer related topic. For some members such a meeting was their first contact.

Although the people who came into the groups in this way do not appear to differ significantly from those in the other categories, they were less satisfied by their initial contact than some of the others.

This is not to say that they were all disenchanted, some gave quite a positive view,

"The first one? Eh, I can't remember who was talking. I think it was a sister from the L--- Hospital. And she was very interesting." Sandra

and

"I think the first speaker I was interested in so I went back. Then they spoke about this series of lectures which I was very interested in hearing." Annette

But some women were less well suited either by the speaker or by the topic.

"I think it was a speaker maybe.. the stress one, the one about breast reconstruction. Its okay for those with small bosoms, but well, it wasn't really for me.." Tessa

and

"Yes, the first meeting I went to was the wrong meeting for me. It was a psychologist and he.. I couldn't. How can I put it? I couldn't relate to HIM...Also that particular type of meeting brings things to the front. I usually find people you usually, when you come to meetings like this, are still tearful. You're emotional and all the rest of it, and you don't know an awful lot of people there. You're kind of nervous. You're not yourself." Nancy

Women got to know about the groups, and attended their first meeting in a fairly haphazard way. If they first attended when there was an outside speaker they were less likely to express a positive feeling about it. It had not stopped any of those quoted from continuing, but it was not what they had expected. Although they might expect information about the disease, the main reason that this group of participants gave for seeking out the group was to get in contact with other people and to share experience. Thus, to arrive at a meeting where there was an outside speaker talking about a disease related topic could be off-putting. Once again it seems crucial that people are given a realistic idea of what the group does, and *when* it does it.

There was no doubt that some people in the group, and particularly those who have been involved for some time did want more information, and so they should get it. But for newcomers this may not be the best first contact with the group. Indeed there were some speakers who gave talks that were difficult and frightening to listen to.

CONCLUSIONS ON FIRST MEETING

From the reported experience of going along to the first group meeting it seemed that those who continued to attend the self help groups had their expectations of groups both met and changed. That is, they were not presented with a group of elderly wrecks but a selection of individuals determined to live their lives as best they could, and who derived support from being together.

Analysis of the type of meeting that was first attended revealed some points presented here in summary.

- The differences that arise in the patterning between groups were indicative of both the range of meetings that any group had, but also reflected their overall organisation and orientation.

- As so many people were involved at the beginning of a group this raises issues about participation and control as a factor in maintaining membership.

- Those groups which had a high professional presence seemed to have a different entry pattern to other groups, linked in to their organisational orientation.

- Informal meetings seemed to be the easiest mode of entry, while speakers were relatively unpopular. This relates to the issues previously raised about contact and support during illness (and perhaps also to professionals in the group).

CHANGES IN THE GROUPS

The groups themselves were not unaware of the issues affecting newcomers. By the end of the observation period most groups had raised it as an open issue, and all but one had made changes in their organisation of meetings to address the issue.

One group (D) had always regarded it as something requiring attention, and had always had an entry policy. This worked well on the whole. Because of the nature of the groups and general openness to new members, the prescribed route was sometimes not strictly adhered to, and newcomers would come to the group in other ways. On the whole this was not too problematic, partly because the nature and functioning of that group was flexible and responsive.

One group (B) did not need a strict entry policy as all members and usually potential members were known to each other at some level before attendance. As most people who might join the group were visited by a group member this made the need for a stated policy less essential. All group members were aware when there was a new member and steps were taken to make them feel welcome. The site and locality of the group facilitated this.

Group C operated in a similar way, but they designated certain meetings as being "suitable" for new members and thus would encourage women to go along to these. Potential members would, anyhow, be visited by Frances, the nurse in the group. It is questionable whether this did, in the perception of the women, constitute a visit by a group member. It did mean that new members had established some sort of contact before attending a meeting.

In the remaining three groups no specific or special meetings had been arranged for new members, although members were aware of which meetings might be "better" for first time participants. Group E, although organised by professionals who would usually have met women before they attended the group, became caught up in the dilemma of what role they ought to play in the self help group. The group had no policy for new members, and the social workers did not see it as their role to deal with new members. This was conclusively changed by one member,

"I sat there for a while and nobody took any notice of me. And I thought this was a bit off. We've changed that now. I'm actually secretary of the group now. And we make sure that new people are met at the door. There has to be someone there anyway, as you know its a social work building and we have to keep the door locked. But someone will always meet any new faces and introduce them." Clara

So Clara lost no time in translating her own experience into a lever for changing the policy in the group, and making what had been a rather loose arrangement into a much stricter one, where the women themselves took the responsibility for new members.

Similarly group F tightened up on their policy of meeting people at the door. They had always arranged their meetings so that tea came first, and people were able to talk before the

meeting started. (People always do talk before the "official" bit got going but it was an original idea to completely reverse the order.) It worked very well.

Group A recognised that there were difficulties surrounding new members, as they might sit un-noticed in the somewhat large meetings. By the end of the field work they did not have a well implemented strategy for dealing with this. Some attempts were made that were not thought through, or discussed in the group as a whole, and which did not work. For example, at one meeting new members were asked by the group leader to stand up and declare themselves. One of these women commented afterwards she thought she was going to faint at the time. Certainly it does seem to be an unduly stressful thing to ask of women who have come along to a meeting for the first time.

This group did have ideas about how to cope with new members and was not unaware of the problems that faced them. They did not however seem to manage to put these ideas into a coherent practise. Changes did occur in the group after the time of this study, which addressed the issue of new members.

Overall, the groups were sensitive to the needs and dilemmas facing new members, and they relied on their own experience and the experiences of others to review their policy and practice. Having a professional in the group as the initial point of contact did not mean that there was a thought out policy for new members. In one group the women themselves brought up this issue and dealt with it, with the help of the professionals.

WHAT KEEPS PEOPLE IN THE GROUPS?

This section looks at what people perceive they get out of being in a group, and what they identify as its drawbacks, and how important they view professional input and relations.

It is important to see what people get out of being in a self help group, what it is that keeps them going along to a group, sometimes for many years. Whereas other authors have concentrated on the activities in a group (Robinson and Henry 1977) or on the organisational difficulty (Richardson 1983). The intention in this section is to explore the subjective experience of being in a group. What's in it? What's in it for you? are questions that have not been asked in self help groups of this sort before.

Knight et al (1980) looked at the experience of being in a self help group by questionnaire, but not by interview. The methodology throughout this study attempts to access the experiential aspect, and was of particular importance here. Methods used in previous studies (participant observation, postal questionnaires) would not necessarily tap this particular area. It was important that questioning is not a threat to the group. The interviews, therefore, took place after regular contact with groups (participant observation). The interviewer and interviewee had a shared experience that allowed people to be honest about the drawbacks. The data from the follow up interviews is used in this section.

Different groups functioned in different ways and people within those groups had a personal experience of being a member that was unique to their group. It was, therefore, surprising that a high consistency of responses appeared between groups. Thus there were many general, non-specific elements held in common, but differences in specific access to activities or roles. Where professionals were involved in the groups, there were sometimes differences in the latter, while the former remained similar between groups. If groups are to be encouraged, then it is important to ascertain what people get out of them and thus future potential members might be guided in what the group might do for them, and what it may not do.

The question of the drawbacks of self help groups has not been systematically studied in cancer self help groups. Yet it was apparent that the group members did not feel the group was entirely without cost. In this study the group members were encouraged to talk for themselves.

BEING IN A GROUP - BENEFITS

All but one of those interviewed concluded that the advantages of the groups outweighed the disadvantages. On the whole what people got out of the group did not differ remarkably from one group to the next, although some things might receive different relative emphasis. The one woman for whom there were more drawbacks than benefits did not continue a high participation in the group, but she did not abandon it entirely. She maintained contact with the group by receiving the group program. Presumably most people who found the group of little benefit stopped attending meetings, and were therefore not available for this study.

Responses suggest that women derive psychosocial support from the groups. They no longer felt isolated, were reassured by the support they received and gave and the normality they felt. They appreciated the time other members gave them. They often said their mood was affected by being in the group, and drew strength when other people did well, or achieved a good death. On a more practical level, they became better informed, came to know their rights, and felt enabled to deal with professionals. In addition some groups sometimes provided access to a nurse who helped validate their health needs.

The greatest benefit for woman was that they no longer felt isolated, and they realised others had found their experiences difficult too. They did not even have to make much use of this knowledge, it was the very fact that people who had gone through the same experience were available to talk to. This acted as a means of reassurance and support of a type that was certainly not available within the health services (or if it was only to a very few). It could not be provided by friends and family, no matter how well intentioned.

"A certain reassurance, and knowledge of course, that there is, if ye like, if I want to talk to anybody, I can...because only someone who has suffered the same as you can possibly understand. I mean, my husband couldn't begin." Sheila

It wasn't only the contact with someone, it was also the time they would allow you over and above what you might now expect of relatives and friends. Some women said that they felt that friends and family had got tired of hearing them 'go on about it'. Peters-Golden (1982) found that over half of 100 women with breast cancer she interviewed felt that people avoided them, and 72% felt 'misunderstood'. The group contact was seen as a reciprocal relationship with turn taking. There was no doubt that for these women the type of relationship that they were getting in the group was not available for them elsewhere. These women had normal social networks.

"I feel I get a lot of support. When I was ill, that time. All these lovely friends I'd made there. I've got good friends from before - my own circle of friends. But you feel the need. Yes they are all very good they all ring me up. It was nice to know that they cared. And I felt that if there was anything I wanted, worried about, I'd probably get in touch. I use Jeanette the most, y'know if something's worrying me. And she comes out with some snappy answers (laughs) and it's usually sensible." Lily

People also indicated that when they helped other people they were aware that they were also being helped themselves (Riessman 1976) although it was something that they appreciated fairly slowly.

"When we last spoke, I suppose I felt that I wasn't doing much. Well, I'm not doing much more, but I realised that every time I spoke to someone, well, that was a help wasn't it. A help for them, and for me too, to feel useful" Ethel

The actual group meetings helped some peoples' mood. They were in the simplest terms "cheered up".

"I'm quite happy to go there. And you come away feeling alright. That you've actually spoken to people that's just like yourself. There's no sad face or anything." Nancy

Thus dealing with the fact of living with cancer seemed to be one of the main themes in the groups. It was possible to go on and live a life.

"It's really trying to reassure people that come that I'd say, to give them hope. Because y'know, at first you've got cancer, it depresses you. I'd say it's to give them hope, and also they want to try and help other people." Vivienne

The helping of other people took many forms, talking about cancer openly, coming to terms with the disease, taking on roles in the group, etc. People also got encouragement from the group, both directly, through specific interactions, and indirectly, through seeing other people. This was regarded as a potentially dangerous area by some professionals (see chapter 6). But people in the groups did draw encouragement from someone else who "does well".

"It's reassuring that somebody's got the same as you, and they're coming on. And you're a wee bit backwards. So it's time you were coming on. Ah think it lifts them out of themselves a bit. Because they think they are the only ones. And then they come into the group and they see she's had - and look at her now! It sort of gives them a bit of courage to stop feeling sorry for themselves, and get on with it." Lynda

So these people were assured that they were essentially normal. Within the medical system they had little information and no reference group, so they had no idea as to how they were "getting on". They had to rely on the sparse contact with the consultant. At the group people were relatively open and honest about their own medical condition; they got some sort of hope, not only of life, but of normality. It lifted that stereotype of the cancer ward, and pushed people into re-evaluation of cancer as a killer.

"Its just to reassure the people thats had the operation and eh, Mrs W for instance and Jane C---. They had their operation 3 or 4 years ago, and they look so well. And I think they just try and show you that its not the end of the world. You can carry on." Mrs Hatton

People drew encouragement from each other in this way, but they are also aware they themselves acted as models for other people in the group. Some people in the groups used this as a means of encouraging themselves.

"There's other people there that have been given a short time to live, much shorter than me. And they're there 10 years after. So I think this is what you want to pick up on as well.

And I hope that for somebody new that comes I can say, I am well." Nora

There was a subtle shift in the emphasis on this in some of the groups. The particular distinction fell between those groups which defined themselves as dealing with more terminal disease (usually the general cancer groups). The emphasis there was on what one could still achieve, what one was doing. The difference was subtle but worthwhile mentioning. In some groups they approached terminal stages and death in an open way, and remained involved in the group. In other groups, members who were unwell sometimes stayed away from the group during that time. It seemed from the observations in this study, that newer groups found the deterioration of members difficult to cope with. As they dealt with this, as a group, they were more able to handle health difficulties in members.

"In the last year (name) has died. That was a shock to us all, as she was so young. It was hard as we didn't know how everyone would react. I mean I didn't know how I would handle it, but we muddled through. And she came, in the end, to a few meetings. And some of us went to the funeral. We did talk about it in the group. V. announced it. I'm not sure about that. And I don't know what I would do if it were me who was ill - stay away I expect."Lena

People also gained access to information. The group, in essence, became expert in its own area and became well acquainted not only with the facts and experience of the disease, but also about the local services available. Some offered this systematically to outsiders (eg the call line of group F). Much of this information was gained through sharing experiences about how the system of health care worked. Other, more factual information came through invited speakers. Where professionals were involved in a group, the members had direct access to health information and reassurance. Some groups were unaware and then surprised to hear that

they knew more about some things than the experts. Thus one group was approached by social workers for information about the availability of grants for people with debilitating illnesses.

The experience of being in the group, and the new areas it brought people into contact with, sometimes had quite an effect on individuals.

"Although when I got into this (group) it was like 2 years after. It was still a long way to go till I came to terms with it. And though now, I'll always *hate* having had it, hate having had cancer - I've come to terms with it as much as I ever will.

Because that was another thing about (the group), you had all this information. And I only heard about Kubler-Ross* through (the group). And eh, I went on the Kubler-Ross course. Its helped me enormously. Not just coping with the cancer experience, but life - and life's problems as well...its broadened me as a person. Its given me loads of confidence." Diane

Diane then went on to list a whole set of things that she had done, including giving seminars to professionals, addressing a hall of 300 people. There was no doubt that she had gained a great deal from being in the group.

Those people who were involved in a group that had a specialist nurse in regular contact also said that they got access to a health professional by going to the group. They could take along their lumps and fears to her (it was always a woman) and she would either reassure them that it was okay, or (more usually) encourage them to take it along to their doctor, or mention it at the next check up. The nurses were quite comfortable with this practice. Interestingly, the group members would approach the nurse specialists with health worries, but did not mention that they went to the social workers with other difficulties. They also did not, to my knowledge, approach speakers about personal worries and problems.

There was no doubt that these women were uncertain about their health, they needed the reassurance that it was a legitimate complaint to take to their GP or to mention at a check up. They were fearful of being labelled the "neurotic woman".

"I had thought about going to see my doctor, but well, I wasn't sure. And I thought, if its nothing he'll just think that I'm wasting his time. So I was worried about the discharge for a while, but then I remembered to mention it to (nurse counsellor) at the meeting. She said I should go to him, and so I did. But I didn't feel so bad then, even though it was only a normal thing" Pamela

This is particularly poignant in view of the fact that these people had all been diagnosed as having cancer. If these women felt uncertain in accessing the formal services, how much more difficult must it be for others?

Most of the women in the groups said that they had aches and pains that no-one in the formal services has ever told them about. They got the reassurance that these were normal in

* Kubler-Ross (1970) introduced a therapeutic approach to death and dying.

the group, but that was not the same as getting it from a medical person. They continued to be reluctant to take their health worries to a professional.

Several reasons were given for this, which included a lack of confidence in their own judgement (potentially something that was heightened in women with non-palpable lumps). They often lacked confidence in their own GP, perhaps because of their experience there with the cancer, and acknowledging that she or he was not an expert in this area. There was also a feeling that they were taking up valuable medical time with something that would be classified as trivial by the specialist. This conflicts with ideas held about cancer as very serious and life threatening.

SUMMARY

The advantages of being in a self help group included contact with other people who were in a similar position. Members could voice their fears, concerns and achievements in a receptive forum, and they need not worry that they were 'going on a bit'. This sort of contact was not available to them elsewhere. Their experiences were validated as normal, both in what they had been through, and in what they were currently experiencing in readjustment. They could use their experiences in a productive and helpful way. Sharing in the experience of others helped them face changes in their health status and, if need be, approach their own death. In some groups it was also possible for people to explore new roles for themselves. This was more accessible in those groups which encouraged wider participation, and which were self run.

The group also provided access to information about how to cope with cancer in their lives, as an everyday reality, as well as about local services. This was facilitated by their contact with professionals, either within or outwith the group. They also had access to information from expert speakers as well as, in some groups, a qualified nurse. In those groups where a nurse was in regular contact, the women made use of her skills in evaluating their health concerns. People seemed less likely to use the expertise of the social workers. Whether nurse specialists in general would accept informal health queries within a self help group setting is not clear, but might be something they have to consider if they get involved in groups of this kind.

BEING IN A GROUP - DRAWBACKS

Although other authors (eg Mantell 1983, Fallowfield 1988) have identified some drawbacks of self help groups, few have actually asked the participants in the groups what they experienced. In this study all interviewees were asked about the drawbacks of being in a cancer self help group. On the whole responses fell into two categories, one relating to the organisation and practical aspects of the group, and the other to more personal experiences

within the group. There seemed to be little difference between groups with more or less professional involvement.

There was a notable consistency about drawbacks between groups. Most members were concerned about the size of the group. There was an idea of an optimum number. As most of them threatened to exceed that, some members voiced concern that the group might grow too large and therefore impersonal. Where people had addressed this in their group, they felt that several small, but linked groups were far better than one large group. There was a concern that they, and new members would be intimidated by large numbers. The only time this was less likely to be a problem was at lectures from outside speakers, where there was less emphasis on member interaction.

Similarly some people voiced concern that the gap between meetings (where this was one month) was sometimes too long for the support they wanted. Indeed, most of the groups had other opportunities to meet, but for some groups this was an irregular practice. For those groups that met once a week no such concern was apparent. Most of the groups seemed to be moving towards organising more, rather than less contact. The one exception was group F, where the professional leaders of the group were resisting organising more meetings, but encouraging the members to do so themselves. So the groups were sensitive to the needs of their members. In terms of ideas for future groups this too should be borne in mind.

Some people found travelling to the meetings difficult, especially in winter evenings. In particular this was a drawback for those people in city centre groups who had to travel some miles from the suburbs. It was not a concern in those groups based in a small town or village. This too should be noted by future group enablers. Travel arrangements were also a concern for more disabled members, but in group D, a volunteer driver scheme was organised to overcome this.

Those people who were more involved in the organisation of the group identified particular drawbacks in the group. For some funding the group was a difficulty, but for each group it was a relative difficulty. For example, one group (A) was finding it impossible to get enough funds to maintain their monthly meetings (rent etc), while for other groups (D and F) the amount of money that they were talking about was for major developments and was in the thousands. But funding remained for each group something of concern, although the professionally run groups enjoyed slightly more security than the others in terms of premises which were organised by the professionals. Funding was not a simple difficulty, because groups were aware that they were not really in the business of massive fund-raising, nor were they unaware that any money they might get would have strings.

"We have been invited to apply for some social service money, so that looks, well, possible. But we are all concerned that if we get it there may be conditions. You don't get given money like that without someone wanting to say what you do with it." Sarah

In a similar way those groups who had done it very much on their own were greatly concerned about the possibility of professional take over and the increasing pressure of bureaucracy. They were determined not to become institutionalised, but for what they wished to do there seemed to be little alternative. As one member put it,

“We seem to be moving rapidly towards institutionalisation with our eyes wide open.” Sarah

It was said by several people that the relations with professionals outwith the group were problematic. This was of concern for the professionals in the groups as well. The social workers in group E and the nurse specialists involved in the other groups shared a concern about the groups' relations and image with local professionals. They did not wish to be seen as threatening to their authority, nor to be 'pinching their patients'. Not only did groups wish to work with professionals, but also they had to be treated by them as patients. All the groups went out of their way to try and develop good working relationships with local professionals, sometimes acquiescing to them, but it was a problematic area.

“What they don't seem to realise, and you must bear this in mind, is that the last thing that we need, with everything else that we have got to do, is to have to deal with bad feeling from doctors. So, for the sake of the energy and the sanity of the group members, especially those of us who come into most contact with them, they must be nursed along.” Lena

The expression was apt.

Where there were professionals involved within the group this relationship was not seen as problematic, indeed people were pleased that they were there. In group E, many of the women were happy to let the social workers organise the group, while others recognised that they wished to change some things. So people were more concerned about the view other professionals had, and felt that the professionals in the group were an integral part of it.

Some members felt that the group had too many professional speakers. Such comments mainly came from people who were in groups that had few social meetings on their programs. This implies they were not getting the support they wanted at those meetings, information was of secondary importance.

In some of these groups the mutual support fitted in and around speakers. Groups used speakers to legitimise themselves, and by doing so almost undercut their primary function. In their efforts to develop relations with the medical profession and to be seen not to exclude them, (as well as provide information to group members) speakers were invited to the group. Sometimes the balance of time was not controlled, and people found themselves with no time for talking. This was most likely to be a difficulty in group E, which was the most strongly professionally organised. There were also other complaints, rather more serious, about speakers.

A few people said they felt the group was too much of a commitment. Although most members regulated their own input to the group (as shown in the previous section), some members were less able to do so. These were usually the core members, who would be telephoned by others and generally took on more organisational responsibility.

This was particularly a difficulty in two groups. In one group (D) many of the members were not in a state of health where they would have been expected to do half of the things that they did. For those women the complaint was of tiredness, and the frailty and lack of obedience in their own body, through ill-health. They were determined to help others, and found it difficult to draw limits on that. This was something that some professionals were aware of, and a few tried to help out with (see chapter 6 on professional relations with groups).

In the other group (A) a complex set of factors operated that rendered one woman as the highly visible, harassed leader of the group. By a variety of means (and this included apparent apathy in the other members) she was left with most of the tasks relating to the group organisation. Most of these she subsequently jealously guarded. But significantly, she was the only individual to complain about the stress of being a core member. She complained that she did not have enough time, and she didn't. She had taken on the full responsibility of the group, and involved herself as a personal contact for several people, as well as doing hospital visits etc. She found it difficult to delegate tasks to others who were keen to take them on. When she was persuaded to do so, she remained critical of their efforts, and thus undermined their contribution.

"I knew that (name) had a lot to do, so I offered to write to the companies who had given us money in the past. I suppose if I'd known I would have shown her the letter first, but it seemed fairly straightforward to me. But when I'd done it and sent them, she wasn't happy with the wording of the letter. Well I tried, but I don't think I'll volunteer for anything else." Celia

This is the sort of difficulty that might be helped by having someone outside the group offering advice on a consultancy basis.

By contrast most other people talked about not having enough time to do all the things that they would like to have done. They wanted to involve more people, get others to help out a bit more, but they had set their limits.

Many members were concerned about lack of feedback about the group. They were interested in their public image, and were keen to get feedback from the research. In particular they were aware that some people came to the group only once, or twice and then did not come again. They would have liked to have known why.

"You don't really hear why people don't come again, like if they come once. Eh they don't come again. And you think, what didn't they get? If you feel you have looked after them as far as normal." Pamela

One woman suggested it might be addressed in the current study, and it is a recurring feature in the literature. Unfortunately what prevented the group finding out for themselves also inhibits research. As people take the responsibility themselves of attending or not attending a self help group, then it is an intrusion to follow them up to know why. Although this type of research has been done in other areas, eg screening (see French et al 1982; Hobbs et al 1980) it was not seen as compatible with the philosophy of self determination in a self help group. It does remain an interesting area of potential enquiry. The follow up interviews might have tapped this area, but none of those interviewed left the group in the six month period.

In group F, where members had a telephone call line, feedback was important - particularly with difficult calls. The group did what it could to reduce this source of potential anxiety by their regular peer support and meetings with the professional back up team. Volunteers did ask callers to report back, but few did.

The members of self help groups were not then people who were unaware of the problems of their own group organisation. No matter how enthusiastic anyone was about their group, most of them were aware that groups of that type did not appeal to everyone. For some they saw this as a general feeling that individuals have to groups,

"I think there can be (drawbacks). There are people who won't join groups if there's any drawbacks. So they try them out. Some people don't like groups anyway. But they can try them out - and if they don't like them, then fair enough. They've got to find their own way out, or their own solutions. I think if there's drawbacks you don't belong. You don't have to. You're not being forced into it."
Jeanette

So the free choice of members is upheld.

Some people did hint at what they thought that people did not like about the group when they say things like, "Well there are some people who just don't want to know". That is they were coping with having cancer by using denial. They do not want to be reminded that they have had the disease.

Some women had heard stories of why some people never returned to the group. Invariably it was something that occurred outside the immediate group meeting, for example,

L: "She said I didn't come again after that night. She said, 'I had nightmares.'"

S: "Did she?"

L "A lady about forty something. 'You did?' She said, 'Yes.' She said to me...Well, you've been to a meeting (addressed to me and I nod) and I couldn't see anything. 'Well,' she said, 'I had nightmares.' she said. The two ladies who she gave a lift home said they couldn't go through this chemotherapy again. And they were quite poorly. So she said it must have been those two. So, what a shame, but she said she'd still like to be on the mailing list." Lily

This woman had in the first instance approached Lily for information on chemotherapy, and the reported conversation took place in the waiting room at a large cancer hospital. It was unfortunate that this woman did have that experience at that time, and certainly going to a cancer group does make it more likely. She felt she had no other potential source of information about chemotherapy. What this woman heard was a personal opinion based on personal experience. Certainly the data in this study suggests that no-one found chemotherapy a pleasant, easy or even a neutral experience. Some way of giving people realistic information must be found.

Several people felt that talking about cancer was a drawback in the group. For some of the groups it remained very much a hidden agenda. Going along to such a group the members were aware that they might engage in a direct conversation about cancer. They were aware that others in the group were at a different stage in the disease from themselves, and that chance comments may resurrect their fear of recurrence or metastasis. But they were aware that they faced this everywhere. They also knew that other people in the group were in a similar situation. After a couple of visits to a group it was clearer where they stood in relation to the amount of openness that existed about the disease. For some groups and individuals it was an open topic, less so for others. But what was remarkable was the way in which people carefully told their experiences, taking into account their listener. This is commented on further in chapter 7 on legitimization.

"Well, you have to be careful, because with someone you don't know, they may be at a group, but you don't know much about them. I'm always ehm, careful. I don't want to put someone off, or make them feel that they're worse than they are."
notes: Madge

This caution was not only conceived because of a wish to avoid overtly medical topics (which also has its protective influence) but a wish to take care of other people that were there. So everyone would initially edit how they talked to someone they don't know. It was certainly not the confessional life history typical of Alcoholics Anonymous.

Unfortunately, the speakers that came along to the group were not always so aware or tactful. At one meeting of group E (notably a group with high professional input), a surgeon delivered the medical facts about the clinical aspects of cancer very clearly. He pointed out that once cancer had been diagnosed it had already been in the body for some time, that it was likely to have spread elsewhere, and talked about the limits of treatments - radiotherapy, chemotherapy etc.

During his talk a couple of women got up and left, he continued. Afterwards one woman commented,

"Did you see J-- get up? Well you know what he said about not having radiotherapy first but keeping it in reserve? Well, she had radiotherapy when she had her op, and she just said that she thought, 'I've got nothing in reserve, I've got nothing in reserve.'" Irma

This was something that was unlikely to happen with a group of people who were aware of their own sensitivity. In some way it addresses the criticisms about these groups - that they scare people (see chapter 6). During the participant observation period in these groups, the most scary stories came from the professionals. The incident related above actually occurred in a group that was organised by social workers, and perhaps illustrates that even they could not protect against inappropriate interactions in a group. Perhaps if the women themselves had approached that particular speaker he might have had more of a sense of the group membership. Indeed the difficulties in assessing where responsibility lay in this group was highlighted by this incident. The women themselves felt that they had no right to challenge or stop the speaker, and the social workers afterwards commented that they felt the information was not appropriate for the group, but that it was up to the women to do something about it.

This occurred not only in instances where the topic was in itself scary, but also individual people became wary of a particular speaker, or the information that they were giving. This could happen despite the best intentions.

"I was about in tears when I came home. Because she said - Are we doing enough ourselves? And she went into, they're onto this tack about maybe your diet having something to do with it. And I don't know, maybe I was just having one of those days. But she thoroughly depressed me. I'd have walked out of there if I'd had the courage. And I felt she was saying it all to me." Sandra

SUMMARY

The drawbacks that people in the group talked about seemed to fall into two categories - those about the organisation of the group, and more personal comments about group participation. The former included practical issues, like the timing, size and program of the group meetings. Others related to underlying organisational issues, like funding and relations with professionals; even where professionals were involved within the groups the relations with external professionals was an area of concern. These were fairly common to all groups, regardless of professional involvement. The personal drawbacks were more likely to relate to feelings people had about the group, and worries they had eg about people who don't return to the group, or who are offered help on a telephone line. Members accepted that the group would not suit everyone, and admitted that the group was likely to make people think and talk about cancer. In the group setting, most people took care to judge their audience before talking about cancer and thus protected themselves and others. Speakers in the group were generally sensitive to this also, but on some occasions they mis-judged the pitch of a talk.

These drawbacks were commonly cited by many members of each group. There seemed to be no major clustering or responses by group, which suggests that all the groups were aware of the potential difficulties associated in participation. The drawbacks of being in a group are similar to the difficulties people envisage who do not want to be involved in a support group. Of the 18% of people who declined to attend a mixed support group for people with cancer, their friends and family, Plant et al (1987) found that they felt they were well enough

informed, that they had practical difficulties with transport and that they disliked groups or wanted to forget about cancer and not hear about other people's problems.

In comparing the drawbacks as members saw them, they coincide somewhat with those offered by professionals (see chapter 6). These will only be mentioned briefly here. Professionals outwith the groups were inclined to mention far more drawbacks than members, and they felt that more professional input would help. These professionals were also keener to put limits on the group. Things that the groups saw as an advantage eg the mix of people was a potential disadvantage for professionals. The major difficulty that professionals voiced - that people would discuss their treatment(s) in an uninformed way and confuse each other - was something that members were aware of and took steps to control. Their motivation for doing so was to avoid unnecessary upset, as well as to protect themselves against criticism. Indeed, it appeared that professional speakers were as likely to confuse people as it became clear that different professionals held differing views as to the "best" treatment for breast cancer.

The relations that groups had with professionals were important, and these will be examined in another chapter. However it is clear from these data that having a professional in the group does not greatly change what individual seem to get out of the group. There are advantages and disadvantages in both arrangements, and it may be that people oriented to certain groups, or remained in them because they were happy with that particular set up.

Overall the group members, not surprisingly, felt that the benefits outweighed the drawbacks for them. They were prepared to deal with the organisational problems in the group for the opportunity of support and help from other members. Many participated in the group to some extent beyond simply attending the group meeting. The single available example of one person who withdrew from active participation because of disenchantment with the group maintained some contact. There were a number of people who seemed to maintain similar contact. Of necessity the sample is biased in favour of those who continue to attend meetings, and it can only be surmised that there are a number of people for whom the advantages of the group did not compensate for the drawbacks, and they did not remain in the group. It may be interesting in future studies to sample the views of those on the group mailing list. Some of the difficulties of this will be apparent in the next section which focuses on member participation.

PARTICIPATION

Self help groups seem able to function effectively with widely varying participation by members and professionals. Some organisational forms worked better than others and these will be examined. It was clear that where professionals took on an organisational role this affected member participation and was difficult to change. If groups are encouraged to evolve, it is important that this is recognised.

Data regarding the range and levels of involvement that women experienced was derived from the interviews with members and supported by participant observation of the

group meetings. Participation in self help groups is not easy to assess. Many of the groups include people as 'members' who remain on the mailing list but who do not attend meetings. So participation can range from receiving a newsletter, to organising group meetings, publicity etc. This range had been found in other studies (eg Richardson and Goodman 1983)

Each of the groups in the study was organised according to its own aims, needs and constraints. However each member was different in what they expected from the group and also in terms of their own experiences that brought them into the group. So it was not surprising that the range and depth of participation within and between groups varied. There has also been an assumption in the literature that participation is an essential function of involvement in self help, and that is a benefit rather than a cost. This is not wholly supported by this study.

The range of activities in a group was to some extent a measure of potential participation (see appendix i for details). All the groups held a regular meeting where members could come along and participate to the extent they wished. For most of the groups in this study these meetings took place once a month or once a week. In addition to this meeting (which incidentally not all "members" attended) there might be other types of meeting that dealt with specific issues, for example one group had regular "spiritual renewal" meetings. These meetings were attended by a number of members, some of whom might not in fact attend the regular open meetings. Groups also had organisational meetings, where the group business was discussed as a whole (as opposed to those meetings for fund raising etc) and these usually but not consistently were given the label of "Committee" meeting. Other meetings might include those that dealt with specific aspects of the group organisation, like fund raising, or organisation towards a specific event eg a Christmas fair.

One group (F) also had meetings where volunteers who worked on the telephone line, got together to support each other and to discuss any difficult calls that they might have had. This sometimes involved professionals. No other group seemed to have a meeting set aside specifically for this purpose, ie. no other group organised specific support meetings. Which is not to say that women acting in supporting roles did not get support themselves - often this support was maintained in a more haphazard and less formalized way at other meetings or contacts.

Other instances where people might collect together, were arranged smaller groups. These often took place in a different venue from the core (monthly or weekly) meetings and served a different function. This was a time when women would get together in pairs and small groups to talk in a more personal way, or at least in a more visibly personal way than they did at larger meetings. Two groups had these as coffee mornings as a regular and publicized feature of their activities, while one other had them at sporadic intervals, one incorporated similar activities into their drop-in centre and one had a weekly morning session.

This mainly covers those organised meetings within the groups apart from those times when groups would organise specific activities, eg relaxation, which might be a short series, or indeed, in some instances, developed into an apparently permanent feature.

In addition to this, the group members got together in a variety of ways, ranging from formal training and information sessions to less visible personal contacts. The groups in Edinburgh prompted a local professional to organise a series of informative lectures which were attended by members of three of the groups.

In terms of further participation, each of the groups differed in the extent and regularity of contact. In all groups there were people who kept in touch with one another for a variety of reasons, eg they might live nearby. Quite a few people kept in telephone contact, and not only with group members, but with other people who never came to the group, and who had no desire to do so. Thus the effects of support in the groups overflowed to people who had no direct contact with it, except through one specific individual.

On the whole this type of contact was maintained on a personal level and no attempt was made to formalize it. Some women had their names on the program for the group and were therefore more likely to be phoned up at random, by members or by others outside the group. The exception to this was group F which had a formal system of volunteers who were trained and who ran the telephone line.

In some groups there was a policy of visiting others in hospital. Group members who had gone in for further treatment were often visited by other group members. Sometimes a hospital consultant would ask individual members to talk to individual patients. It was also not unusual for members to chum each other along for out-patient treatments eg chemotherapy, or to help each other with practical issues like transport.

It was also practice in some groups to have a couple of people who would regularly visit other people at home. This would keep them in contact with the group as they reached a terminal stage or provided an outside contact during an illness episode.

So, the range of possible participation within any one group was extensive. It might be possible to attend a monthly meeting only, but it was also possible to take the opportunity to visit someone in hospital, or at home, or to act as a telephone volunteer. Needless to say different people did different things at the various stages of their involvement in the group. Some went through a whole range of participation during their time in the group, while others attended a few sporadic meetings. For some people receiving (and presumably reading) a newsletter was enough to be classified as a member.

This section, therefore, attempts to look at the experience of these different levels of participation in the group, what it meant to the women who were involved, and how they moved around participation and negotiated new levels of involvement for themselves. In

particular the involvement of professionals and how this affected participation is important and receives attention here, as well as in the next chapter.

RANGE AND LEVELS OF PARTICIPATION

What the group aims to do, and achieve, is of interest here, but particularly what individuals within the group do, see themselves as doing and what is achieved out of doing it.

The concept of participation was something that, although of importance for the group as a whole as well as the individual, was negotiable. The whole concept of being an active participant in a group was not simply that you wrote the newsletter, or that you visited three people in hospital. As one of the 'leaders' in one of the groups pointed out,

S: "So you feel that everyone in the group plays an active part in some way or another?"

V: "Yes, definitely. It may not be something that they do every meeting or every week, but there is at some point when that person is the right person to speak to someone else. That's what I mean. That they may one night come along and just sit and chat about what ever is going on. But another night they may come and speak to someone and help that patient. Maybe, ehm, not that the new patient tells them, but it may come out later. Y'know, that just "having spoken to that person that night, the difference it made when I went home", and "I thought I had helped someone, or wasn't so worried." This happens often." Vivienne

So at a meeting people might interact with each other in a way that is beneficial to one or both. In the first instance it seemed that Vivienne meant that people were matched up and therefore you shared your specific personal experience with someone else. But it was far more general, and indeed far more random than that. The assertion was backed up when several people in the course of the interviews gave examples of contacts of this kind, that had made an impact on them or helped them during a difficult time. It was apparent that some sort of supportive milieu was engendered and although all the interactions did not have this impact it seemed that they have some sort of generally beneficial supportive function.

Vivienne frequently referred to women in the group as "patients". Initially it seemed that she used this terminology to make an impression. But she continued this usage, and felt quite strongly that... "we are patients". At other times the orientation of the group and the philosophies that Vivienne as an individual put forward were quite in contradiction to this stand. This point is further developed in the chapter on legitimization.

Meetings were seen by most of the members as the prime focus of the group, this was perhaps because of their own attendance at these meetings but also might have been because they occurred regularly and provided an organised focus. This was not to say that there were not people who did not go to these meetings. There were quite a few members who never attended meetings for a variety of reasons, but they all knew about them. Unlike some of the other activities that had a less high profile, these meetings were regular and publicized.

Generally speaking they were the means by which many people had their first contact with the group, as a group.

There was a wide range of possible participation at a meeting. It took some little time to discern this as an observer, but there was little doubt that different women take their attendance at the group meeting as an opportunity to participate in a variety of ways. It was also clear that this varied over time and some individuals would be very active at certain meetings and less active at others. Their perception of their own participation was revealing. Some women felt that they did very little.

"I don't think I contribute anything. Apart from turning up, and seeing them all." notes: Jenny

"I don't really do anything. I'm not very active, I just go along. If I'm feeling a bit down in the mouth - and you just forget about it." Wilma

"I just talk to people. Maybe bring in some new ideas. Just being there is, yes." Kirsty

Clearly what they contributed to the group was something that few of these women had ever really seriously questioned. They went along to the group meetings, and did not consider that a great contribution. During the course of the interviews many of them said that they had not realized how much they actually did at meetings, and that talking to others was of such value for both participants.

Some women were much more aware of their contribution and said that they hoped they helped people that came. It seemed that once people had been going along to the group for a while that there was a certain expectation that they would contribute through talking to other people.

"After a while you feel like chipping in your bit. And then I gave a talk myself at a meeting in November" Ursula

"We all make conscious efforts, well I do, not to only talk to anyone I know at the meetings. Always talk to new people. Make them feel welcome. Now we have a policy on that, old people to look after the new." Clara

So there appeared to be a process by which people coming into the group were brought to a recognition that their presence and their ability to listen and talk with others was a valuable contribution. Having recognised this, they were able to welcome and encourage others in the same way. Once women had been coming to the group for some time they did recognise that they had a particular role to play.

"This was three years ago (started coming to the group). I was going to give up. I've heard most of the speakers, but for the new members its good for them as well. It gives some core and stability." Nancy

It was apparent, then, that there were limits to what the group could provide in terms of information (from speakers) but that women recognised the reciprocal aim of the group, and

having benefited they would put back into the group. Although, this was not always the case, and some group members felt that it was hard to get older members to stay and contribute.

For some of the "old stagers" this was taken quite seriously.

SP: "Do you actually find yourself talking to people like that (intimately) quite a lot?"

S: "Oh yes. Everybody knows me. I'm one of the older, established ones there. Nearly everybody knows me. I feel very involved when I'm there. In fact I find sometimes I feel as though I've neglected people. I come home and a person's been sat next to me while I've been talking, while the talk's been going on, and I've not talked to them properly. And if I know them, I'll phone them up and say "Sorry, I never got round to speaking to you, you dashed off." Because I feel guilty at not having spoken to the person I was sat next to. But I know most of them, and like I say, they all know me. I'm quite a chatterbox really." Sonya

There was a recognition of the value of talking with one another, and the 'older' members of the groups regarded it as quite serious business. Sonya did provide a lively focus in the group, and it was true that many women in the group knew her and talked with her. What also seemed apparent in this particular group (E) was the recognition of the value of the 'older' members. Although it was something that was apparent in other groups nowhere did it have such a high profile as here. The professional organisers in the group encouraged her, and others in a similar position to take on this role. They recognised the importance of 'older' members in the group. This may have been because at that point the group was undergoing some attempts at structural change with the professional organisers trying to make the group "more self help". This meant that they wanted the members to take on more responsibility for running the group. This coincided with a few of the longer term members looking to leave the group. It was not clear how closely these were related.

So one of the major contributions in a group was the fact of *being* there. Once someone was at a group meeting there was a wealth of things that they could do to participate, many of which were not highly visible, or indeed tangible. They listened to each other, talked with each other and engaged in a myriad of interactions that showed interest, empathy and caring.

More visible, perhaps because more verbal, were the contributions from those women in the groups who asked the questions of the speaker, or who lightened a moment in the group by a witty comment. One woman was quite clear that one of her major contributions was putting her "tuppenceworth in". It was sometimes a professional within the group that prompted discussion and questions. The women themselves in most groups felt that they started discussions, and those who were prominent members often saw themselves as directing the group. On the whole when women were asked what they did or contributed in the group they were much more likely to say that they did very little unless they were obviously involved in some defined role. They, therefore did not share with researchers and professionals a strong

emphasis on recognition of participation by members as being a major defining characteristic of self help groups.

At the meetings there were people who did a variety of things. These included taking care of the new members, welcoming people at the door, making the tea, doing the washing up, and making cakes for the meetings. Some of these might seem trivial, but they were essential things that facilitated a meeting for everyone else. It was low key, so it was easily taken for granted and the women themselves often did not see its importance. (It is also typical women's work).

The more tangible and visible activities did indicate belonging in the group. But over and above this feeling that women seemed to like being useful in a practical sense, they were also a means by which communication was facilitated. Women who washed up the dishes together were often sharing their feelings about cancer and their own ways of coping.

"I remember a meeting I went to and, people were talking and I thought - 'I'm no good at this'. I felt so inadequate. And I went with another girl to the kitchens to make tea, and I said "Y'know, I feel so inadequate, everyone else seems so professional". She turned round and said, "I'm glad you said that, because that's how I feel". Liza

It might also be a time when the group members could approach the nurse in the group with something that had been bothering her,

"We used to have the meetings in my house, which was quite a lot of work having the front room ready for them. Sometimes we had a big crowd, and, but it did lose. When we moved to the hall to begin with it sort of, became a bit more impersonal. I mean, what, for instance I would go through to the kitchen to wash up the tea cups up. And if they were coming up to their hospital appointment, or something, they would come through to the kitchen, and it would give them time to get it off their chest. Whereas in the hall its that bit more formal." (specialist nurse)

Essentially all and any of the things that women might do within the group meetings could be aids to communicating, either with each other or with a speaker.

Nearly all the groups had an overt or covert recognition of fluctuations in participation. Those women who were interviewed at follow up had often changed their level of input. Most of them had either maintained or increased what they did at meetings. One woman had talked tentatively about being a telephone volunteer, and at the follow up interview had enrolled for the next training course. Another had spoken to a meeting of professionals about the group, and another had appeared on a local radio station. In one group two members had appeared on television talking about self help. Many members had been involved at that level for several years, and were happy with it. One or two had attended fewer meetings, often through illness or because of changes in their own or family circumstances. Some had started to withdraw from the group a little, by only going along to certain selected meetings. So participation at group meetings is influenced by several things, including health status, length of time in the

group, and personal life changes. It also became clear that professional involvement influenced participation.

Participation within the meetings was often the first step to integration in the group, and further participation. This aided the overall aim of most cancer self help groups - to enable people to gain more confidence and control. Some groups seemed from their organisation to recognise this quite clearly and had few participation difficulties. They got people involved in small tasks with other members quite soon after joining. This was a deliberate strategy in some groups (eg groups F and B). It was also successful in group C, where the nurse facilitating the group encouraged this as a means of maintaining a self help rather than a professionally directed group. Interestingly, most members wanted to help others, and would have willingly been more involved in this. The organisation of the group could either facilitate this, or hinder it. It was notable that group E, with the most directive input from professionals found it hardest to get people involved, particularly at an organisational level. It thus seemed that where professionals were involved the members were a little more reluctant to participate along the traditional self help model.

OUTSIDE OF MEETINGS

None of the groups in this study, and possibly no group that fits under the umbrella of self help, stopped at group meetings. If nothing else, there had to be some organisation of those meetings, and thus some form of activity outwith them. All of the groups were involved in offering help and support in other contexts. Many people in the group supported each other in some ways and some groups offered support to non-members.

Support to members was mainly available in the group meetings, but most of the groups made available some telephone numbers of members for group and general use. One group (F) organised a telephone support line available to members and public alike. In addition many members swapped addresses and telephone numbers and developed their own support systems within the group.

"When I feel really bad, I phone up B-- I'm doing it quite a bit at the moment, since this recurrence, and I don't feel like going to the group. My hair has all fallen out. At least I know that its (the group's) still there. But I feel okay that I can phone B--, and sometimes J-- sorts me out, and I don't feel bad about that. When she had a hard time last year, she used to phone me. I'm not sure how much I helped, but she helps me now (begins to cry)." Lily

Members helped each other in practical ways too. They accompanied each other along to appointments, or for radiotherapy treatments. They visited each other at home, and on occasion, in hospital. Where members became ill, and died, some of the groups kept up their support, helped with practical arrangements for relatives etc.

Indeed the groups were stretched in helping their own members. They also looked to help others too. Thus they offered to visit women in the breast treatment unit, at the request of

the consultant, and linked with the specialist nurse to provide some community contact for newly treated women.

Not all members were involved in these support activities. They were often organised on a very personal basis, between people who had grown closer through the group.

GROUP ORGANISATION

"I became really pretty involved in it. Sort of went to committee meetings. Which weren't like, I hate committees, but its not like that type of committee meeting, y'know. It's just. It's a shame that they can't change the wording for it because I think it puts a lot of people off. To me, I actually find the committee meetings like any other group meeting, y'know. Because if there is anything niggling or worrying you. There was always somebody there who perhaps had been through it, or perhaps got over it. So it helped me in that way." Clara

All the groups had evolved some sort of organisation that directed the group on the whole, that was supposed to be representative of the group. None of them had completely abandoned the idea of a representative decision making body. Even if they had tried to avoid this in the first instance, they were generally forced into having some sort of nominal "committee" for the sake of registering as a charity, or for grant applications. A representative committee was usually seen as the mode, par excellence, of democratic organisation, and any attempts that the groups made to evolve other means of organisation were thwarted by this dominantly held idea.

However, the ways in which these were implemented and organised differed considerably from group to group and operated with varying success. Some groups were highly organised, but also highly participatory (eg group F) and others were hardly organised at all (apparently) but participatory (eg group B).

One thing that seemed to be of common concern was to get people in the groups involved in the organisation of the group, after all the group was supposed to be run by the members. This was a concern both for the more active group members as well as the professionals who were organising the group. To this end either posts were allocated and/or committees set up. Getting members to help in organisational tasks was more difficult than involving them in mutual support. In group E, the professionals running the group had great difficulty in getting members involved in organising the group, while the members took on the mutual aid functions fairly easily. Indeed, as has been seen, few people went along to a group with any clear idea about self help, and participation.

A core group often evolved which was very active in the group while other people in the group maintained a somewhat passive receptive role. These more active members understood that going along to the group was a form of participation and did not expect that everyone would want to be involved in organisation. The implication of the theory of self help and mutual aid, with equal participation of members was difficult to maintain in hard reality.

"Well, at the end of the day *someone* has to find the funds to keep the group going, or answer the phone, or whatever." Vivienne

The way that women got involved in the committee, however it ran, was interesting because it not only reflected their own ideas about the group and their participation in it, but also the structure and to a great extent the ideology of the organising members.

So for some people it was a relatively straightforward move and they were voted on, or they decided to go along to a committee meeting and thus became an integrated part of it. Many women in the groups did not want to be involved "that much" and comments like those made by Wilma were fairly standard,

"Oh no. I'm a member, that's all. I know the committee. I know Mrs. D. I know them all. But I'm just a member. I'm not a committee sort of person. No."
Wilma

Many people saw themselves as not a "committee sort of person" in a similar way that they indicated when asked if they had ever been involved in any other self help group, that they were not really "a group sort of person".

So who went into the committee and how did they get there? With the exception of one active group member who had wanted to be involved in the committee, all the women interviewed had taken on the role with a degree of stated reluctance. For some women who had started up the group it was quite apparent that these roles had fallen on them because they had been involved in starting the group and other members expected it of them.

"Because you're the one who had the idea in the first place and you have managed to do so much, then others seem to expect that you can go on doing it. I was quite happy to do it in the first place, but now, well I'm not sure I couldn't do with a rest." Ethel

Many of the people who were on the group committees had been members from the beginning of the group's existence. Some of them did feel that they had been somewhat forced into the role by circumstance, or coerced into it.

SP: "Do you feel you play an active part in the group then?"

S: "Not really. I'm on the committee. But I was put on the committee before I knew I was on the committee. (laughs) I think I make up the numbers. And if they need typing done I'm quite happy to do that. I'm an ex-typist. I like to help out - need letters done. I've told V-- I'll do that but ehm, I don't think I'm going to take these classes. Mainly because I haven't got transport. And I couldn't run out at any time to see someone. Most of these others have got transport." Sandra

Sandra here outlined a number of reasons that were given by different women in relation to their not wishing to get more involved in what the group was doing. Although she was a member of the committee she did not see herself as being a great participant. Yet she did appear to be one of the more active members of the group. The way she saw herself as co-opted onto the committee was repeated by other women in other groups.

"I'm actually secretary of the group now. I don't know how I got the job, but I did and that's it." Clara

People did present an account that implied they were pushed into these positions. It was never really quite clear whether they gave these accounts out of a sense of not wishing to be seen as putting themselves forward, or whether they really did not want those roles and were pushed into it. Certainly during the time of the fieldwork no-one was obviously forced into something that they did not want to do. Indeed in some groups quite the opposite happened, and women's willingness was dampened. Groups were, on the whole, administered by a small number of individuals and there were often people on the "committee" who did not play a very active part. This seemed to be the case whether or not a professional was involved.

Most of these cancer self help group did not want to have a committee in the first instance. For many of them it was a necessity imposed by the need to either affiliate to a national organisation (like group B) or when they got to a certain point in terms of numbers and organisation, to register as a charity. One group (D) in particular fought against this imposition, and were adamant that they would adopt offices of secretary and such like in name only. They wanted to maintain a strong mutual aid model.

For those women who were on the committee, unless they were one of the main organising members they did not find the task a difficult one.

"Well that (being on the committee) only involves a couple of meetings a year. Yes. That's one in about October, when we decide what we're going to have the following year. Y'know, drawing up the program and, eh, then we're having one a week today." Clara

and

"As (nurse counsellor) said, there is no committee as such, whoever turns up is part of the committee. At first I didn't go because I thought it was one of those committees that's very straight laced. But the last committee meeting I did go to. So, eh. I really enjoyed it. It was good. It was just like a get together, discussing the topics we enjoyed more than the others, which should be repeated for new members." Mrs Norton

Committee meetings were in fact quite different for each group, some of them being more serious than others but on the whole they did not fit into the commonly held idea of a committee. It seems that despite efforts, by more involved members and professional organisers alike, to make these meetings non threatening, and to encourage women to come along to them, all the groups found it difficult to get people involved in the group organisation. Thus the costs of participation need to be recognised. Some of the active members found that they became too involved in terms of demands on their time and energy. They came to a point where they wanted 'a rest' (see Ethel above). So the notion of serial reciprocity (Richardson and Goodman 1983) was not easy in practise. The groups need to recognise this, and to provide some means by which people can move into and out of the more demanding organisational roles. Professionals who might be involved in groups need to acknowledge this,

and groups themselves should recognise it. The professionals in these groups who were most successful at facilitating participation had presented the group as self run from the onset. The greatest difficulty lay in the group where professionals had 'run' the group.

So it seems that when people are classified as group members or not depending on whether they attend a group meeting is in no way indicative of their status within the group and bears only a slight relation to their actual participation. It is quite possible for someone to go to every group meeting, but to participate minimally, although this "minimal" might be essential and of great benefit to herself and others. It is also possible for someone who goes along to only one group meeting in several months who may also be participating widely in other aspects of the group functioning.

All the people interviewed or contacted during the participant observation period played some part in the group. Many did not recognise that in going along to help themselves they were also helping others. When questioned about it they became aware that perhaps they were contributing more than they had expected, as all could recall at least one instance where they felt that sharing their experience or listening to someone else had been of mutual benefit.

People were involved in many activities outwith the group meetings, including fund raising, organising events, inviting speakers, writing letters, answering telephones, being a first contact for the group, visiting other members in hospital or at home. In the more organised groups most of the members played some small role in the group outwith the meetings. The pattern of participation was unique for each individual, and often changed over time. As people moved on in the groups they adopted different roles and this was seen most clearly at the follow up interviews. All those interviewed remained in the group, bar one woman who had left the area. Most people had maintained their input to the groups, with one or two exceptions who had withdrawn through ill health. Some others had increased their participation, and taken new steps. One woman had talked tentatively about being a telephone volunteer, and at the follow up interview had enrolled for the next training course. Another had spoken to a meeting of professionals about the group, and another had appeared on a local radio station. In one group two members had appeared on television talking about self help.

Significantly most of these changes and developments of individuals reflected the changes in the groups. The most organised groups provided more opportunities for different forms of participation, and it was the members of these groups who were doing more at follow up.

WHAT AFFECTS PARTICIPATION

Participation in self help groups means being involved in the supportive or mutual aid functions of the group and the organisation of the group itself. This involvement is not directly linked to satisfaction of members in the group. Each participated in a different way. Some were closely involved in many aspects of participation, others attended meetings, others were

content to attend only a few informative lectures. Many of those interviewed expressed a willingness to be more involved in support, but not in the organisation of the group. Participation is both a benefit and a drawback for members - they feel involved in the group, but it takes up time. There were people who expressed involvement with their group while being minimal participants. However, most members who remained in the group were involved at some level, and this seemed to help. They were both helping and helped. Both personal and organisational factors seem to influence participation.

From a personal point of view participation was effected by the very problem that brought people into the group. Health status influenced how much people could do, so that when members were ill, they were unlikely to attend the group. In group D in particular, where many members dealt with severe illness and disability, this clearly affected their involvement. The members of this group were more likely to find it difficult to even physically get to meetings.

People often felt that they did not have the confidence or the skills to be more involved in the group. They felt that they could not, for example, function as a first contact for the group because they might not know what to say. Members who were doing these tasks admitted to similar feelings, but had learnt through experience.

Time constraints and other commitments might prevent members from being more involved, and they changed their degree of participation as these constraints changed.

“When we spoke last time like this I had wanted to do a bit more typing and things for the group. Now we have easier premises and (daughter) is at University, its a bit easier and I manage to do a bit more. Not as much as I thought I might, but still...” Annette

People who had been in the group for longer tended to become more involved, and once people were involved in one aspect of the group, it seemed easier to participate in others. If someone developed a friendship with another, more involved, member then they were likely to become more involved too. People often linked together to help each other in this way.

“Madge and I do it. We just started by writing to some of the bigger firms, just to see. And we were surprised when some of them sent back, well (laughs) not always money, but at least nice letters. It was easier because there was two of us.” Bessie

If people came along to the group, having been involved in other groups they were more likely to become involved quickly. Similarly, if they had expectations of involvement, that also seemed to make it easier. People were also likely to review the group in the light of their own experience, and sometimes became involved in trying to modify the group on that basis. The policy about new members was revised in this way in most of the groups (see chapter 4).

Overall, people seemed to be fairly willing to be involved in the group, but wanted to remain in control of that and not feel pushed beyond what they felt they could cope with. A

variety of personal factors influenced their participation in the group, including health status, other commitments, relations within the group and past experience of groups and their own experiences within their present group. A major influence was also the opportunity for appropriate involvement, which concerns the organisation of the group.

As it is mainly members who organise the group and are also involved in it, then it might be expected that the groups shifted and changed according to its membership. As has become clear, not all members participate in the group to the same level. In particular people are less likely to be involved in the organisational aspects of the group, and this sometimes fell to a few core members. From this study there appeared to be some ways of organising the groups that facilitated participation, and others that hindered it. In particular, core members had to be careful about replicating a similar relationship with less active members as the group had with professionals.

Participation in the group seemed to be facilitated by some non specific factors. Thus the general atmosphere at meetings helped or hindered sharing support. Different speakers had different effects on group participation and discussion depending on their subject and style. Each meeting involved different members, and some were better facilitators than others.

More specific structures and policies, however, were discernible that helped or hindered participation. These seemed to affect organisational involvement. Groups which encouraged a small amount of input from all members seemed to stimulate more general participation. They were more likely to encourage people to take on small and non-threatening tasks, usually as part of a small sub-group. Thus members might help to seal and address envelopes, or be asked their opinion of a speaker. These groups, although they differentiated clearly the support and organisational aspects of the group, were sometimes able to integrate them to allow general involvement. Thus they incorporated discussions of group 'business' at meetings, integrating both organisation and support. Different aspects of group organisation were dealt with by small pockets of members, who shared tasks. Thus a funding group might devise letters, check them with the group as a whole for comment, type them etc. Each task was broken down, and shared. In this way newer participants learn from accompanying more experienced members, and any task was shared with the overall group. In this way the group gained in experience, and began keeping records of pitfalls and achievements which helped new people coming in. As there was opportunity to share organisational experiences as well as personal experiences, people were able to talk about difficulties and successes. Thus they shared responsibility and fears.

This was easier in groups with no dominant leadership. All the groups studied here expressed difficulties with encouraging participation. In two groups there were particular problems. It seemed these were primarily related to organisation of the group. However one of these groups (E) was organised by professional social workers who were also active in recruiting women into the group. Although the group was advertised as 'self help' perhaps

this professional involvement influenced who heard about and attended the group, it certainly influenced women's perceptions of their roles (see chapter 6). In group E most of the women had more or less maintained their participation constant, despite the efforts of the group leaders to increase the level of input. In effect, this sort of professionally led group unwittingly discouraged active participation of members. The other professionally initiated group (C) had more or less been taken over by members, and they all continued to 'muck in' at all levels. It seems that, as Robertson and Reed-Purvis (1991) suggest, professionally initiated groups have problems of their own.

One group, which was participant initiated had problems because of a dominant leader. At follow up interview a stalemate seemed to have been reached, with other members saying they wished to do more but being persistently blocked by this one member. The group leader, by contrast, emphasised that she had difficulty in getting people to take on roles in the group. The issue seemed to be about style of leadership and control rather than strength of leadership or personality. Another "strong" leader in group F had stimulated wide participation in the group, delegated most tasks and gradually withdrew from the group itself over the next year or so. These two styles of leadership seemed to mimic the styles presented by the professionals outlined above. While one had followed self help principles from the start, the other had slipped, perhaps inadvertently, into suggesting a division between those who did certain organisational tasks and those who did not.

CONCLUSION

Group members reported a range of benefits from being involved in a self help group. In particular they were less isolated, and were helped by their contact with others in the same situation to deal with cancer as part of their everyday lives. Their own experiences were put into context, and even made useful for others by mutual sharing. They also gained access to information and expertise both of the members and through the group program of speakers, and in some groups they had direct access to a specialist nurse who helped them deal with their health and illness fears. These benefits were seen by them to outweigh the drawbacks of membership.

Drawbacks included being likely to think about cancer more often, and sometimes being made aware of information that they found difficult. Members were also concerned about organisational issues, like the timing and size of group meetings, and their reluctance to participate here. Active group members also had to deal with uncertainty about people who came along to one meeting only, or telephone callers whom they had no means of following up.

In terms of participation in the group, it appeared from these data that over the time of the study most of those interviewed increased their participation. This ranged from talking to others at meetings, to visiting others in hospital, or organising speakers for the group. The level of participation was apparently influenced by the structure of the group, with those holding a clear idea of self help principles maintaining more general member involvement. This

seemed to influence general participation regardless of whether professionals or members were organising the group. In those groups run by professionals, there seemed to be greater difficulty for women to take on aspects of organisation that professionals had previously done. Thus it proved very difficult to make a professionally organised group 'more self help' if they did not have that ethos from the beginning.

The next chapter looks at professional involvement in self help in more detail and explores these issues further.

CHAPTER 6 : PROFESSIONALS

This chapter deals with the views and concerns of professionals. It demonstrates that professionals associated with the groups held mixed views about groups which were sometimes unrealistic. Few of the professionals interviewed had a clear idea of self help, and fewer still had seriously considered their input to the groups. The data also suggest that some professionals anxieties about the groups were unfounded.

Data was derived from interviews with fourteen professionals, including paramedical and medical staff, hospice workers and social workers. The interview followed a semi-structured schedule, covering the main areas of contact with, and knowledge about, the groups. This included individual views of benefits and drawbacks of self help groups and comments about the possible professional contact and the future of these groups in relation to professional workers in the health and social services. In addition less structured conversations with professionals attending the groups (eg as speakers) were used to inform the work. This was analysed as a whole, as it was assumed that 'being professional' gave people a certain status vis a vis the groups. The number of professionals involved was so small as to make any comparison between professional groups difficult, nor was a group by group analysis indicated.

Professional workers had a wide variety of contacts with the groups, from weekly contact to once a year input in the form of an organised lecture. Views about the groups varied from professionals who had a fairly clear and realistic idea of the groups and their activities, to those who did not. Many had not considered the nature of their own relationship with the groups. Most professionals commented on the possible benefits and drawbacks in the groups and these are examined in some detail. Many professional workers wanted more professional involvement with groups, with little consideration of how that might change the nature of their functioning. A few were keen that the groups should be more assertive about their input to professionals, and act as a pressure group for change.

The groups had differing contact with professionals. This ranged from those who were set up solely or principally by members (groups A,B,D,F) and those set up mainly by professionals (groups C and E). The contact with professionals could be construed roughly from professionals working 'inside' the groups - ie where they held organisational responsibility, to professionals 'outside' the group who were invited in to participate. At the time of the study all of the groups had some contact with professionals as speakers to meetings. Group A had access to and some limited, but fairly regular, contact with a nurse specialist. Groups C and E had regular, organisational input from a nurse specialist, with additional organisational input from social workers in group E. Two (groups D and F) had organised an array of professional back up, but these professionals had no organisational responsibilities. Only one (group B) had little other input from professionals; it was the only group which was part of a national organisation.

PROFESSIONAL CONTACT WITH GROUPS

These data suggest that groups do not attempt to exist in isolation from the formal services, and all had some contact with local professionals. The professionals interviewed ranged from those who had limited, often once-only direct contact with the groups, to those who were involved with the groups on a regular basis. Only three of the professionals saw their involvement in the group as a part of their job, or an interpretation of their job description. Some had incorporated their contact with the group into their work, and for others their contact with the group was seen to be quite distinct from the rest of their professional work.

The different roles that professionals played in the group, from speaker to trainer are the focus here. The roles of 'inside' professionals in professionally initiated groups is examined, and the difficulties and advantages that arose from that. Contacts with professionals was used by the groups as a means of legitimation, and this will be dealt with in chapter 7.

Some professionals had quite limited contact with the groups. The medical staff, in particular, tended to have been to only one or two meetings, as an invited speaker. The contact had been arranged by the group, not the professional.

"Nothing to do with me personally, but purely because of the job that I have. I've been approached by various groups in Edinburgh to go and spend some time with them. I suppose each of the groups I've only been to once."

This comment from a consultant surgeon was fairly typical of the medical profession as a whole. Once they had given the talk to a group it was unusual for them to continue contact or go again of their own accord.

This speaker made an attempt to break down professional barriers and to de-formalise the contact. Although he would have been invited to speak quite specifically, he calls it 'spending time' with the groups, there is no reference to a lecture or anything directive. This implies recognition of a different role for professionals in this context. He does not characterise the relationship as that of patient and doctor, nor quite as co-worker. He appears to take a stand that was quite comfortable for the groups, that acknowledges their experiences and his own expertise. Others give a slightly different view,

"I met with them and that was fine. But that was highly focussed in on the problems of having breast cancer. That is a group of women who had breast cancer. That for me was very straightforward - because most of the questions there were related to how doctors manage breast cancer and so on. Again that seemed to me that that was all right."

This role of speaker in the group was shared by most of the professionals.

"Yes, we do come across them (self help groups). I don't know how much *formal* contact we have with them in the sense of ehm, day-to-day interaction with them. We, from time to time are invited, maybe to go and speak to several groups or a specific group."

One difficulty in changing the usual power relationship of professional/patient was the possibility that speakers might come face to face with their "own patients".

"It's potentially a dodgy area for them (speakers)...they could come along and meet their patients. On the other hand that could happen to a GP as well. And I think that its important, and the women do appreciate this, that the questions are not personalized, not their particular treatment. Because that's the danger..."

Other speakers were also aware of this possibility, and they were careful to emphasise general queries, and refused to deal with specific cases.

"People can ask you in general, about things that matter to them personally, eg Do you believe in breast conservation? What do you think about diets? and can listen to the answer."

Thus the information is given over in a way that is not threatening to either the woman or the professional. But it was something that had been considered by the people in the group.

As well as the short, succinct contact of being a solicited speaker in a group, medical professionals were approached by the group for other input.

"I've also been approached, by (group D) in particular to help with fund-raising, which is a separate, executive exercise. They want people in positions of authority to help them get money."

And on the whole they are willing to do this, often on the basis of quite limited contact with the group. These professionals seemed to recognise their own function in the legitimisation of the group. They are willing to work along with the groups, while recognising the differenced between their own professionalism and the group, and being able to make use of that.

A similar support / legitimising function was also mentioned, this time in relation to the literature produced by the groups.

"I did, a year or two ago, vet one of the leaflets that the group produced on eh, problems patients have after mastectomy or radiotherapy for breast cancer. They drew up their views - and I tidied up some aspects of the radiation problems.

And I think that they are distributing them...they drew it up themselves, discussed it with the surgeons and I suggested some corrections in relation to the radiotherapy aspects."

The group again approached a professional to add credence to what they were doing. Although the information in the leaflet is referred to as "their views" it was not made apparent why the group's "views" should need comment on by a professional. However it became clearer that the information in the leaflet was not purely the personal experience of having had cancer but also included health information. The inclusion of "medical fact" would therefore require confirming by the experts, and it seems that this was easily achieved. The seriousness with which the leaflets were treated in the production stage was not carried through to the distribution, as this particular radiologist did not have a copy of the leaflet, and was uncertain

where to get one. When asked his opinion on this sort of exercise, he replied that he thought that it was "acceptable so long as it is accurate". The role was restricted to overseer.

The amount of contact with the group did not necessarily reflect the importance of that particular professional for the group. The most prestigious individuals were cited by the group as being important for the group, although they may only have spoken or lectured once or twice. This is commented on further in the chapter on legitimisation. Some individuals were slightly less clear what their role actually was, or had been.

"We don't have any direct dealings with the self help groups that's been set up. We were involved, in fact, in setting it up -we helped set it up. Largely Prof G when I say 'we'. (the specialist nurse) etc went to their first meeting. So in a way we encourage it. But we don't directly have anything to do with the involvement of the group. Dr S probably has a little more than we do. The only direct contact was when I was asked to speak on the treatment of breast cancer to the group."

The account offered here differed in emphasis from that offered by the specialist nurse and by the group who saw professional involvement as minimal in setting up the group. The consultant assumes there is still some organised and formal professional input.

Some individuals held very important roles in relation to the groups. Some professionals saw themselves as almost co-workers with the groups, aiming for the same end of the best possible health care (in the widest sense). The professionals and the groups were able to recognise their own limitations and the others' range of expertise. This allowed the groups to benefit from contact with the professional, while the professional often acknowledges a benefit for them in greater insight into the personal experience of having cancer, and how this might influence services. In particular a consultant working in breast screening was cited by many of her professional contemporaries as the person who had most contact with the groups. She is mentioned in the quotes above, yet when asked about her contact with the groups she said,

"I haven't seen much of the groups recently. I've been too busy. And it's a shame as I like to keep in touch with what they are doing. The last time I spoke really to Sarah (main person in group D) was about a year ago. So of course I don't know how far the group has moved in that time..."

I was approached by Vivienne (group leader). She was talking about having another series of meetings or lectures like the other ones that we had here. I hope she did not feel that I was cooling her out as she is very welcome to use the premises but I'm afraid that I cannot agree to be here for a series of meetings just like that. I mean it just is impossible. And also I did want to withdraw a bit too."

Like other professionals Dr S did not have the time to be closely involved in the group. Her 'real' work took precedence, and she found herself unable to attend a series of evening meetings that she had been involved in setting up.

Involvement with these sort of groups was not seen as part of her job. The regularity with which people associated her with the group and her indication of limited contact with the groups went a long way to indicate not only how little contact these groups actually had with

professional people, but also how important that contact was. It was publicised and made visible, and legitimised the group. Not only did the groups cite Dr S as an important professional contact but local professionals saw her in a similar way.

Some professionals were requested by the groups to help them with training or information. This was particularly clear in the "back-up" list of professionals of one of the general cancer groups (group F). They had the support and the practical help of several professional people which included a psychiatric consultant, nurse counsellor and social workers. They not only helped to organise and run training schemes eg. for telephone volunteers, but who were also "on call" to the group members during the telephone times. Anyone who was experiencing difficulties on the call up line could in turn phone one of the professionals for help or advice. This provides a good working model for professionals adopting a consultancy role for groups.

In practice, seeking on the spot help from the back-up professionals was not a regular occurrence. However the function of this professional back up team was also to validate and facilitate the work done by the group on their telephone line.

"It is important that the members support each other. But it is also important that they are not left to deal with things that they cannot cope with. That is the role we have, where they can phone you up if it becomes difficult. It doesn't happen much. You usually find out afterward that there has been some problem."

Thus all the groups had some contact with professionals. The groups that were set up mainly by professionals had a similar range of contact, but in addition professional workers regularly attended group meetings in a more or less professional capacity. This was not without difficulty for them, or the self help aspects of the groups.

One group (group E) had been set up by two social workers (see below). Their work on the ward was changed by the start of a research project to evaluate the work of specialist nurses, and of nurse training. The nurse counsellor was subsequently included.

"I got involved because the social workers at that time were doing it. (They) asked me if I'd like to go to the first meeting. Now they didn't ask me if I wanted to have anything to do with the admin. of the group.

They started off y'know as a pilot scheme...I went to the meeting and the pretext for going was that I'd be interested. That it was about clothes and mastectomy bras and things. I'd be interested in seeing that. So I went as an observer really, took no part in it.

So after one meeting came the next, and so on. In the end I went to all six of the pilot group meetings. But nobody asked me what I thought about it or anything. The patients who came had to fill in a questionnaire to say what they thought but I wasn't part of that and equally I wasn't part of the organising group either."

Nonetheless the nurse counsellor continued in the group and indeed developed a unique role in it. This role was similar to that of another nurse in group (C). For these nurses their professional role is not compromised by contact with the groups, but enhanced. They

were, however, able to use their own acknowledged expertise while reducing the constrictions of the client / expert relationship. The women found these nurse more accessible and contact was more informal than it would have been within the usual service provision. They were therefore less anxious about approaching the nurses for help and advice, particularly advice that allowed them to make better and (for them) easier use of the medical services. The nurse in group C describes it herself.

“What has happened is that it has become quite clear that I have a unique function in the group - which is that people know I'm there. And sometimes people will specifically come along because I'm there. And it's quite obvious once they are there. And its much less difficult than either ringing up and saying can I come and see you - which is a very professional thing y'know like seeing the doctor almost, as if they're going to “come and see” me. Or waiting for patients to come to the clinic here if they have to wait till they bump into me.

Well that may be difficult because they may come to the clinic and I'll be involved with someone else, and I may not actually see them. But they know I'm at the group, and when it comes to coffee time its easy enough to come and ask whatever you want to ask. And I have been shown, y'know little lumps. “How are you” - “Oh I'm fine, I'm fine...well I've actually got this little lump, and I was wondering if I should do anything about it.” And that is actually why she's come (to the group).”

The experience of most of the nurses involved in the groups was very similar - access to professional knowledge was essential for some of those women. The question must arise as to why they must seek it in this way. The nurses seemed happy enough in their role without, it appeared, questioning it further. There was no indication that they were going to change their clinical practice. Indeed they seemed to feel that it would have been to no avail, that women would still wish to approach them in that way, and in that context. It thus seemed to be an implicit part of the functioning of the group, and provided an interesting mix of the group as social support and primary health care access point.

As a profession the nurse counsellors had much in common with the groups. In both cities the individuals in post had fairly regular contact with the groups in their areas. In one instance NB (specialist nurse) had been involved at the beginning of the breast cancer group. She went along to meetings every now and then. Indeed the group seemed to see her as a major contact person within the general medical field. She, however, had a surprisingly different view.

NB: “I haven't actually got a lot to do with the organisation of these groups, did you know that?”

S: “Mmm. But you are involved with (group A)?”

NB: "Well, I was involved at the beginning, yes, but I was...well but the shining light behind (group A) is Vivienne with support from me and from some other professionals, but she is most involved, with Dr S as well. Although Dr S was not as involved as Vivienne was herself. I wouldn't like to claim any, any, I say that (group D) have me as one of the professional people involved just as a name. I presume to give it the authority of, of professional authority. But I'm not in the forward in the organisation of it, or of (group A) apart from a little fund raising event at the beginning."

From this it appears that this nurse counsellor saw her role as fairly minimal, but crucial. She was aware that the groups used her as a legitimating professional, for which she did very little in practice.

By contrast, the two social workers who had "inherited" a group "as part of the job description" were far less certain about their role in the group. Although others saw them as running the group, it was a role that they were not sure whether they wanted to shed or not.

"We meet in the Social service centre, because the social workers are there. It's actually the social workers who actually *run* the group..." Clara

They themselves held a slightly different, and at times contrary view. They inherited a particular set up from previous workers and were finding it difficult to change the group and their role within it. They clearly felt that they were seen as the people who ran the group and the relationship was characterised as that of expert and client. They were not comfortable with that and did attempt to move it to a 'co-worker' type of model, with limited success.

"And the social workers don't feel its their role to be social workers there. I think we're leaders rather than supporting them in the way that we would, or counselling them if they were known to us in our work. We don't take them on as, as clients."

Even these professionals divided off their 'real' job from what they do in the context of the group. It was clear from the interviews with these two social workers that they were quite uncomfortable at times in their contact with the group. On the one hand they felt responsible for running it, and invoked practical reasons why this should be. On the other they were keen to move away from a dependent group, and wished to encourage the women to take on other things.

"I think if there were people willing to do the jobs that we do - we'd let them (sic), but we'd still be there. That would be-we wouldn't withdraw completely. I think we need continuity."

"I think the social worker role is as facilitator. As a facilitator and to ensure continuity, these are the two main things."

This experience of the professionals in this group suggests that there are real difficulties. The idea that professionals can start up a group, then withdraw and still facilitate it did not work in this instance. Once professionals took on roles in relation to the group the members were thereafter unwilling to take over those tasks themselves. It was seen as something that social workers did, and thus outside group members' own sphere. The attempt

to reconstruct the relationship from one of dependence as professional / client to co-worker with differing but important skills was very difficult in this group. The women came into the group mainly through the social workers, and their expectation about the group would be coloured by that.

"We've tried to get them involved, in, well, particularly what they want, like topics (for speakers). I have been trying to get them to take on jobs, but we haven't found that very successful. We feel they like the social workers to do things, and they say "Oh no, that's for social workers." Even down to making the coffee!"

"On a mundane practical level, and the members have said this and I agree with them, it is our job to go and get the coffee ready, or the tea, while the speaker is still speaking. Because that speaker is speaking to members of the group who want to listen to them. And somebody has to make the coffee and therefore we should be the ones doing that. It's their group."

These two quotes came from the two social workers in the group. It seemed that there is some discordance in their views about who should do what.

These and similar issues occupied this group throughout the period of the field work, and were never adequately resolved. They highlighted the difficulties for professional involvement in a group and the delicate balance that was needed to allow the group to function independently while incorporating professional input. No doubt the difficulties in this particular case were emphasised by the change of professionals in the group, and the difference in interpretation of group policy. Whether it was a lack of clear guidance or policy, or a personal inability to sustain the balance, or indeed, just an impossible set up was not clear. The women in the group felt that the social workers should continue to run the group, and were very cautious about taking on tasks that were routinely dealt with by members of other (non professional) groups.

At the same time the professionals held a belief that because of the nature of the problem that it was not possible to have a self help group. There would be no continuity if there were no professionals involved. There was also some notion that women should not be burdened with too much responsibility. These views were unlikely to make the move towards "more self help" easy for either the women or the workers.

SUMMARY: PROFESSIONAL CONTACT WITH GROUPS

A variety of different professionals had a range of contact with the groups. Some had only one-off contact as an invited speaker, ranging through the sample to those who really ran groups. Most of the professionals saw their contact with the groups as mainly outwith their normal professional functioning, even those who did it within their work time. They played roles as speakers, sources of information and figures of support for the groups. An example of good interaction in a consultancy / back-up role is offered. A brief look at a group set up and run by professional workers on self help lines highlights the difficulties of this role in

enabling without disabling the group participants. If groups are to be helped by professionals then these difficulties will need to be addressed.

Of particular interest was the position that nurses took up in the group. They seemed to become sources of support and help for individual women as well as the group. Indeed, they came to provide an extra layer of health care that was both acceptable and accessible to women with diagnosed breast cancer. They did not change their formal practice as a consequence, at least in terms of its organisation. They did, however, manage sometimes to steer women towards the formal services in an appropriate way, which often included some formal contact with themselves in other settings. This relationship was not entirely outwith the professional / patient or client model, but did veer towards a more co-worker type of relationship where each recognised the expertise of the other. The nurses did not attempt, in any of the groups, to take over the group organisation or assume responsibility for its functioning.

By contrast none of the doctors involved in the groups sustained an organisational role or acted as a source of medical expertise to any of the women individually. They would give talks to groups, act as consultants for general difficulties and help with training.

Social workers did not seem to offer people individual help either. In one of the groups they did play a strong organisational role, and seemed to have a model of self help available to them, although this did not work well in one group. They were also involved in support roles in other groups, helping with training and problem solving. One social worker, who was also a group member, was able, through the anonymity of the telephone help line, to guide people towards herself in her professional capacity. In this she was no different than other members of the group who had the same opportunity of offering advice about local services.

Most of the other professionals had limited contact with the groups. None of them saw it as an important part of their job or routinely made contact with the groups. Some of the hospice workers in Edinburgh managed to link in with group D as time went on, and towards the end of the fieldwork that looked like it might become a more consistent liaison.

Whatever role the professionals saw themselves as playing in the group, they were only sometimes aware of their role in legitimising the group. The groups were, by contrast, able to use almost any contact with professionals to help them validate their group. This is developed further in the next chapter. Few of the professionals had given much thought to their contact with the groups, and fewer still to the concepts of self help and what it meant to those involved, including themselves. The groups, by their nature, had been pushed into consideration of these issues, and of their relations with professionals.

PROFESSIONAL VIEWS OF BENEFITS AND DRAWBACKS OF GROUPS

All the professionals interviewed were asked to express their views on the possible benefits and drawbacks of self help groups. They were much more forthcoming on the possible drawbacks, offering a wide range of critical comments based on possible difficulties for individuals, as well as for the groups as a whole. These were akin to much of the members' expectations of groups. Nevertheless they remained generally favourable to the groups, and continued their contact with them.

PROFESSIONAL VIEWS OF BENEFITS

It will be recalled from Chapter 4 that group members had a variety of expectations of the groups and their benefits. In brief, they went along looking for support and information, reassurance and help with self confidence. They did this in the context of feeling isolated with expressed difficulties in communicating with professionals. They were also cautious about meeting other cancer patients who might be unlike themselves, and of talking about cancer. Some came along wanting to help others, feeling that they had got through the worst. Many had already wondered what self help might mean and if there would be professional people at the meetings. By the time they had been in the group for a while they recognised that they were getting social support and felt less isolated. They often felt that they were giving help as well as getting it, and that they were able to talk openly but not exclusively about their health related difficulties. They were able to put their experiences into context, and draw encouragement from other group members. They felt much better informed both by members and professionals, and were pleased about the increased contact the group allowed with professionals. Thus they had come to see the group as fitting in somewhere on their health care system, and accepted a role for professionals in relation to the group. As will be seen in chapter 7, many were able to welcome and make use of professional contact in legitimising their own group.

Professionals seemed to view the groups in isolation and in terms of individual help/change. They had given little consideration to the groups as part of a system of health care. Thus the benefits of participation were seen in individual terms, and their relation to the system as a whole was fairly secondary. Most of those interviewed were cautiously in favour of the groups, and maintained long term relations with them.

On the whole most of the professionals were able to see that the groups were about providing some sort of 'support'.

"I'm sure its the support of each other..."

"Mutual support, eh information."

Others developed this theme further,

"...Because if they work as a group there are differences aren't there, in terms of whether a group is working to give emotional and psychological support to

each other. And that's more or less what they are exclusively about. And to talk to each other - they want to unburden their problems with each other. Or whether its a simple question of somewhere to go on a Monday night - because that's at least one evening when they don't have to pretend that they haven't got an illness. Whether its a coffee evening and its all very superficial and frivolous- but its a form of more physical, psychological support."

There is clearly here an understanding of the many aspects of the groups. Not only can each group be different, but one group might serve different functions in their different activities. This radiologist was surprisingly insightful to the workings of the groups, although he had had fairly limited dealings with them. He himself had ideas about the possibility of a patient support group, and had given this some thought.

Some of the professionals saw the groups as a source of information for people. One professional was involved in organising a series of talks by local health care workers for three of the groups. She worked with one of the group members and saw it as a good opportunity to educate people through the groups. However, she was clear that this should provide the background for the group functioning, and was not its major role, this lay in the support of women by women.

"Actually, I was surprised at how very little the women in the group knew, weren't you? They seemed to not even have the basic information about treatment. Especially considering they had all had *some* experience themselves. That was quite an eye opener for me and made me appreciate how little people do pick up when we talk to them. It seems important that they should have some minimum knowledge.

But...I feel very strongly that they should not feel that they have to know a lot. That isn't really what I see the groups as doing. They should be supporting and possibly counselling people. I did begin to think that really they might have better spent their time doing some counsellor training, although I was surprised at how little they know."

This doctor clearly differentiated between experiential and medical knowledge.

A few professionals (mainly doctors) were keen that groups should become more aware of medical procedures and treatments, in order to make them more understandable for members. They were aware that people stood in awe of doctors, and hospitals, and saw the group as a possible means of helping to address that. This was a benefit for the groups and for professionals.

"There may be ways of using self help groups, indeed, to take some of the mystique out of it all."

Quite a few of the professionals interviewed saw some benefit in the groups in terms of their contact and relationship with professionals. They were clear that this was outside the normal pattern of relations.

"It could be that it's outside the hospital, but it could also be that the patients outnumber the doctor, so in some ways it's helpful."

The group is seen to provide a forum for better communication. For one consultant surgeon this was one of the main values for professionals of a group,

"Yes, one of the ways we learn of patient needs and requirements is I'm sure through looking through groups. Where people are actually willing to talk, where they won't talk in the clinic about their worries, because they're bottling it up."

Where professionals did recognise the need for women to have some support, they felt that it could not be done by themselves because of lack of time and resources. Given the relative power positions of the women and the surgeons, it seemed somewhat remarkable that it should be the women's initiative to try and change this communication pattern.

Certainly a small study done on the content of telephone contacts to one of the group's phone-lines indicated a very high proportion of queries and concerns about communicating with professionals (see Eardley and Brown 1985).

Some professionals (mainly nurses) saw that there was a value not only in going along to the groups for the women, but also that the roles that they might enact there were helpful.

"But I think that a great many of the women get a sense that by belonging to the group they're able to pass on tips. And it makes the experience of having had breast cancer a bit less awful, because you can make some sense of it. 'Well I used it, I used it by going to the group. And y'know being able to cheer somebody else up, or say it wasn't so bad.'...They're either helping or being helped fairly actively, and they sometimes change roles."

This nurse counsellor saw that women were encouraged to be active in the group. This was on the whole maintained at the practical level, and the tips mentioned were as likely to be how to sew up a swimsuit, than how to bring about better communication with the doctor. That was not to say that either one was necessarily any better than the other, but what it did indicate was that these self help groups were probably much less radical in their functioning than professionals on the whole anticipated. The groups were not in reality active in challenging the medical profession. In fact some professionals wished that they were.

This latter view was expressed by some professionals, mainly in encouraging the self help groups as a pressure group. These professionals recognised that the groups may have had something quite radical to offer in terms of giving a public light to their experiences.

"There certainly was a suspicion in the minds of some that medical people really were eh, dissociated from the struggle and the suffering and all the complexities of daily living of these women. And that they were so concerned with their own projects and getting their statistics, that they really did feel kind of like numbers. And they never were listened to or given an opportunity to be followed through by an individual who was interested.

Now I kind of feel that they could make use of that, if its a strong enough feeling, to be a pressure group in such a way that the medical profession is helped to know what kind of service would be useful to them."

This approach certainly made sense, but did not take account of the underlying dependence that the women felt on the medical profession.

In similar ways other professionals made suggestions,

"They could be positively offering something to a young doctor, if it is a young doctor, by having the courage to ask for an explanation..."

"...that there has been a medical problem here, and (they've) come off badly as a result of it. In a way I think they should be sitting down and writing to the consultant to that effect."

The speakers here were not doctors, and in fact doctors questioned about this issue felt quite strongly that the group should not get caught up in these challenges, that they were in fact "personal issues". One doctor stated that he was keen to encourage people to participate in their health care and he saw a role for the group in encouraging people to do that, but specific issues were "in the relationship between the doctor and his (sic) patient."

Two people advocated a radical role for the groups in getting information and in challenging some of the status quo. They were both women themselves, a doctor and a nurse, and were themselves challenging to their own profession. Others felt that the group should take up issues and act as a pressure group, but it was interesting the delineation of the sphere,...

S: "Has the group acted in any way as a pressure group then?"

J: "It hasn't, but it could do. It could do. For example if there were serious problems about obtaining a good prosthesis, things aren't too bad around here, but I think the group are a good medium for expressing things like that....Other things might apply to patients with more advanced disease, who were in chemo or hormone therapy, related to prescription charges or the cost of obtaining a wig."

So the expected sphere of influence was quite narrow, and even when proposed as a pressure group the pressure is maintained in very safe (ie non-medical) ground. This is of course not to say that these areas were not important legitimate concerns for the groups, but rather that they did not fall in line with an indication of them challenging the medical set up, or pushing for radical changes in health care.

SUMMARY: PROFESSIONAL VIEWS OF BENEFITS

So the benefits of being in a self help group, as seen by professionals, included sharing of experiences, but not challenging the medical profession on the basis of those experiences. Taking different roles in the caring and cared for dyad was also seen as important. Opening up good communication with health professionals was a possible benefit to members and professionals alike, and some saw the group acting as a forum for this. That groups might explore other forms of health care was somewhat ambivalently viewed. Similarly the notion that the groups might function as a pressure group was portrayed as a possible benefit, although none of the groups in this study took this up in an active way. These views of possible benefits were fairly congruent with what group members said they got out of the group. Mutual support was high on the list of benefits for both.

Overall there were benefits within boundaries. There was a persistent concern that the groups would overstep some undefined boundary of what constituted 'medicine' and was therefore outwith their competence. Most of the professionals did not realise that the groups were also concerned about overstepping that boundary. They were not there to directly challenge the medical profession. They were fearful of antagonising the medical profession, of jeopardizing their own health care and were concerned to maintain the group in which they were receiving support.

PROFESSIONAL VIEWS OF DRAWBACKS

Professionals in this study saw that groups had benefits for their members and sometimes for professionals too. They also felt that there were drawbacks to self help groups. These are important to consider as this might add further information to what is known of self help groups, and professionals. In addition, if these groups are likely to be encouraged, this information throws light on the interactions of professionals and self help that will help inform any policy decisions for the future.

In Chapter 4 the members gave *their* views of the drawbacks of the groups. In brief, these focussed on the group as an organisation as well as more personal concerns. The former included worries about the size of the group and its potential development into an impersonal meeting. Most people did not want big gaps between meetings and were concerned to reduce that. For some members travel arrangements were difficult, either through disability or distance. Many groups had no funding and wanted to keep a balance between maintaining the group and being drawn into endless fundraising. Linked to this they were concerned about the impression potential funders had of the group, about the need to formalise the group in some way in order to conform. They realised they had to appear legitimate and used their contacts with professionals for that, but not without some concern about professionals taking over and re-defining the group. They were also aware that the organisation of the group had to be maintained and monitored in some way, and they did experience difficulties with this, both in terms of group participation and leadership problems. On a more personal dimension, they voiced concern about over-, or under- commitment, and for some people the group took up a lot of their time. Those involved in running the group sometimes worried that it took up their family time. Others acknowledged the emotional burden upon them, and their difficulty in not responding to a request for help from professionals or members. Many wondered about what people got out of the group, and felt that they needed more feedback on their own input to it. Many member remained concerned about cancer, and about talking about it. Although this was not a drawback in and of itself, they wanted it to remain within limits, and expressed concern about new members in the group. Interestingly, some people felt that there were too many speakers in the group, and that some of them overstepped that boundary and frightened people.

Similarly, analysis of the drawbacks of self help groups mentioned by professionals clustered around the difficulties for the individual, and those that focussed in on the group

itself. These will be dealt with in turn, as the former highlights the views professionals held of the groups and the latter more readily informs their relations with the groups. There seemed to be little difference if the groups were professionally originated or not. Most of the professionals interviewed did not even acknowledge this difference in the groups. Where it was mentioned professionals in groups were seen as a moderating element.

DIFFICULTIES FOR PEOPLE

Professionals were aware that cancer had a strong emotional impact for people, and were concerned about how the group dealt with that. They acknowledged that the illness presented its own difficulties with deterioration, recurrence etc. The management of cancer is medically complex, and professionals were concerned that people might become confused by conflicting information about treatment. Each of these is illustrated and data from this work used to clarify the groups' response to these concerns. An underlying issue for professionals was a concern about people taking individual responsibility in being involved in a health related group that was outwith professional control, with their best interests in mind.

Some professionals were concerned that women going into a group for the first time might be rather shocked at the range of illness in the group,

"I think that the drawbacks can be the sort of problems that arise maybe when the individual sees too many possibilities of complication, all in one go.

You can go along to a group where you find quite a lot of disability, or quite a bit of psychological-emotional disturbance which may well make the person who is going along seeking help more frightened and insecure, more unable to cope with what *might* go wrong in the future."

The speaker here had given talks at some of the groups, and had been involved most closely with group D, where people were indeed ill, but on the whole coping with things very well. It was also one of the groups that set out to deal with a range of illness and death and dying. A consultant surgeon remarked

"...To cope with a woman of 32 whose got two small children whose just had a mastectomy and is panic stricken, but may have 10-15 years to live, may have a normal life span, she just doesn't know, and she's just met one of life's crises. To put that person together with a woman of 68, who knows she's only got a year to live is quite difficult. If these people come together naturally that's fine, and they will find some common ground...I would imagine that is quite difficult..a health club. But if you're to help each other emotionally- reactions to illness etc. that might be difficult."

But no-one was actually able to say that these two women would live their lives as predicted. Indeed it was that living with uncertainty that women found difficult, and where they found their common ground in the group. There was also somehow an assumption that the experience would not be a rewarding one for both of these involved. There was certainly evidence in the observations of the groups that such apparently unlikely liaisons did take place, to mutual benefit. Professionals were less likely to consider that women had contact with each

other at a variety of stages when they were in the hospital ward. All of the professionals interviewed recognised the emotional impact of cancer diagnosis and treatment.

"They're not a patient one day, and a patient the next, and to introduce them to, particularly a mixed group of people at different stages in their disease - complete strangers. I think could be very difficult. I think its different if a woman is in a breast unit, and there's women of all stages in the disease scattered round the ward, and a staff who are completely devoted to that type of treatment, they can then mingle.

Patients in hospital mingle in coffee rooms, smoke rooms, and they pick up wrong ideas and right ideas, and that in itself is an involuntary form of group therapy, a group help system. "

This implies there are emotional needs to be addressed and it is seen appropriate that women of all ages and stages are *put* together in hospital, as if that conveyed some sort of protection. By contrast if they meet, of their own chosing in a self help group, it may be dangerous. Great consideration was voiced about what women spoke about in the group, the concern focussing on how people might react.

One of the nurse counsellors took up a similar point and put it into a fairly realistic context. Her concern was not the possible shock that women might get when they initially went along to a group, (and whether it is shocking or not is highly debatable), but rather that by continued contact in the group they would get to know people and continue to know them when the disease profile changed, and health deteriorated.

"The other point often raised is that women get unduly alarmed by seeing other members have recurrence or even die. And in the time I have been involved in the group, and it may be because I haven't known people that long, it hasn't been that obvious, because people can get a recurrence, and tend not to attend the group then. On the other hand a lot of the women would say - they worry about this anyway. So its better to keep it out in the open than have everyone saying 'Don't be stupid, that's not going to happen, everybody will be fine. It's better to realise."

The observations in the study confirmed this in other groups. The women were very cautious about attending, or in some instances even having contact with the group, at a time when they were ill. Some groups were more set up to deal with recurrent illness than others, eg group D had death and dying firmly on their agenda. Other groups had not yet had to cope with the death of a prominent member yet, although all had dealt with recurrence and metastasis.

In one professionally organised group (E) this was an issue,

"The other problem is that this group has resolved interestingly by ignoring it, is the problem of recurrent disease, and the group just neatly drops, like a hot potato the member who gets too ill to come. And I think that its okay for them to do that - so long as we are here, the professional groupies, to go on visiting that person. But I gather from what I know in other groups, that in some groups they are very supportive when a member goes downhill, and visit, bring flowers and things."

Other groups coped with these difficulties where there was no social work input. This highlights again the differences between groups led by members or professionals. An interesting point is raised about the possible role of professional workers in self help groups

“...there's no nasty lurch for us -its just somebody with advanced disease, and we keep the support going... And I think its important that there is some on-going process, because the group members don't want to take it on.”

It may be that because the professionals did not have cancer that they can offer help more easily. However, self help is about shared experience, and in other groups this meant the shared experience of facing up to death and life with cancer. Participant observation data suggests that the groups which dealt best with deterioration through cancer were not those with the greatest organisational professional input. Some of the professionals talking about the self help groups seemed to recognise this social support,

“(Group B) - were becoming a real community support group...there wasn't a great preoccupation with morbidity, but a very realistic knowledge of what was happening in the group, of who was poorly just now, who had died, that kind of thing. But with no sense that it made the others stiffen with fear, and think 'That's him away, who's next?'”

Thus the group dealt with the reality of the effects of cancer.

Overall professionals feared that in going along to a group, people were having to confront the realities of cancer. They had not fully appreciated that people going along to groups did so not only of their own accord, but also in consideration of these issues (see chapter 3). These data suggest that it is difficult for professionals to accept “patients” acting on their own and taking responsibility for these decisions themselves. As some people were clearly willing to take the ‘risk’ of contact with others with a possibly terminal illness - few professionals had considered what prompted that behaviour.

Although shared experience was seen as a benefit in the groups, professionals had reservations that some people might be frightened by this. They were cautious that women might discuss their treatment and be upset or confused. That groups took great care over these issues (see chapter 7) had not influenced this view.

“What can be difficult is if self help starts to confuse, by people trying too hard, with the best possible intentions...somebody in a self help group starts confusing the patient about the pattern of their illness, and the care they're getting from the medical profession. *I don't think I've come across that*, but I'm very much aware. it borders on the problems we're getting nowadays with alternative medicine.”
(italic added)

Most of the input in the groups about the disease and its treatment came from doctors etc who were invited along to speak at the meetings. Group programs strictly emphasised that there would be no medical advice, the groups were well aware of that possible criticism and took precautions against it. But still the notion of confusion persisted. One of the functions of

the groups was to share *experience* of coping with cancer, and that included treatment regimes. Groups differentiated between experiential and technical knowledge.

Professionals commented that women's knowledge about their cancer and treatment was fairly limited. Few professionals chose to address why that might be so, and where women might get information.

"That is the risk, if a self help group has no medical input. There is always the risk that someone will say, 'Oh I had those pills, and they didn't agree with me' or 'they cured me' or 'When you get put on those pills its pretty serious I can tell you!'"

None of these so called risky statements would be at all risky if doctors felt more confident that people were involved in and understood, at whatever level they could, their own treatment. On the basis of the information available in these data, the suggestion is that communication between medical staff and patients was poor, and people did worry about what was happening to them. One possible way of addressing this, by having some medical input to the groups would have been welcomed by the groups. For many of them their only difficulty was 'at what level?' There was a danger of being overwhelmed or taken over by a professional. Indeed, as indicated earlier, the groups did much to educate themselves and to invite input and contact with medically qualified people.

For some women in the group the most difficult times in the context of the group meetings was being given a whole range of medical facts, including particular risk factors and the possibility of recurrence or death after having had the disease *by a medical speaker*. On one observed occasion this was delivered with little apparent regard for the situation of the women there. Somehow the information if given by a medically qualified speaker in general terms was deemed to be less upsetting than talking to someone else about personal experience. This was an area professionals had not seriously considered.

Professionals were concerned about individual ability to cope with cancer, and that clinically distressed individuals would attend the group.

"She was being helped by focussing on the distress of others. She could project all her fear and all her anxiety onto them, and she didn't have to admit where she was herself...its a coping mechanism that as a society we admire...at the other end of the scale people who strongly deny what's happening to them health-wise. And they are backed up by families who maybe strongly deny. They will seek help inappropriately from a self help group when in fact they are really requiring clinical professional help."

This nurse counsellor has some grasp of the potential complexity of any "coping mechanism". Other professionals held a similar view, that, paradoxically, people who had not really faced up to their illness might be in a group that deals with cancer. It may be that professionals feared that people would see others who were worse off, which was something that the women themselves were aware of (see chapter 4).

Individuals with clinical (psychological) difficulties are not readily identified by professionals. There is seldom a service that screens for psychological distress, so there is a possibility that people might seek help inappropriately in a group. Where professionals offered a back-up to groups it helped deal with this. There was otherwise little help for the groups in identifying individuals with clinical difficulties, or helping to cope in the group, or how to refer on where appropriate. Groups were fairly good, on the whole, at selecting people in and out of the group. Individuals seemed to do that themselves. Clinical problems were not and could not be addressed in the group.

Some professionals felt that those who wished to deny their illness went along to the groups and were distracted by aiming to help other people. Some felt that the group became a major prop for others

"People in a sense, y'know lots of us really almost need to have a worry. And I think that E and perhaps many people in the group are of that nature."

"I felt that evening, that there were those who were terribly open who could make so much of a self help group and who were making so much of their lives. I felt that there were other people there and the group was their reason for being. Take away the group and they wouldn't have a crutch. And these are very crippled, disabled people psychologically, and they're also very frightening people to confront."

So the group was seen for some people to take on too much importance in their lives.

There seemed to be an implication that this was wholly negative, whether other help was available was not addressed. Certainly for one individual the group was of paramount importance in her life, often to the detriment of the group. For most people the group is a part of their lives. Where professionals maintained organisational control the opportunity for over-involvement was less likely, and lack of involvement was the problem.

Other professionals had heard of examples of people who had gone along to the groups and been smothered in help - to the point of personal invasion of privacy.

"She was greatly distressed to find a particular woman in the group latched onto her as somebody she felt she could help - and has phoned and phoned and phoned. has dropped in and has wanted to make a weekly business of a therapeutic visit. Now she is a very private person and she doesn't want people coming around her house. She has found it very hard to put this person off." nurse counsellor

These data suggest this was quite unusual in the self help groups. Few other instances of this sort were reported, either by the women or by other professionals. The groups were seldom organised to the point, or declined, to take names and addresses of those who attend. As a group it was a moot point how responsible they were as a whole for the actions of individual members. On the whole the groups were very cautious about issues relating to privacy and individuality.

A much more common comment from professionals about the groups was less that people would want to give too much, but rather that they might give too little. This more closely resembles the concerns of the groups.

"...That's my biggest concern, that if they're (set up) entirely on their own, then you can have one or two people dominating the whole thing, and using it exclusively for themselves. I imagine that happens in any group, and you try to avoid (it). There are always people who'll want to take too much from a group aren't there?" psychiatrist

Similarly others questioned the motives of people who went along to the self help groups, there was concern that the principles of self help were not fully understood.

"People don't always go along to a self help group with the right motivations do they? They're not going to be Christian and generous to other people - they're going to vomit their own problems onto a group of other people. It's very complicated. Alternative medicine is fraught with the same problems." medical consultant.

This, however was not borne out by what women themselves said. Many of them were concerned to help other people as well as help themselves. It seems that the line between the two (if indeed there is one) is vague. This consultant's association of the group with complementary, or in his words, 'alternative' medicine is interesting. It was difficult to imagine a group that upheld the medical model as closely as the one he referred to.

An attempt has been made, so far, to clarify some of the drawbacks that professionals mentioned about groups that seemed to be rooted in the people involved, rather than the group processes. Professionals were aware that people may seek out the group inappropriately, eg by using it as a means of denying the illness, or of masking more severe clinical problems. They were also concerned that women at different stages of the disease might be mixing, to bad effect, without having considered that the women might benefit from this contact. Professionals were concerned that the group might become too important for some, and become a crutch, rather than a support, or that members might be intrusive in others' lives. A few also mentioned the possibility of odd people in groups pushing 'alternative' or complementary approaches.

Overall, the professionals seemed to be cautious about groups and aware of these potential difficulties, and indeed some of them did arise and the groups members were aware of them too. Nevertheless, few professionals had talked to groups to look at these problems, or how they dealt with them. Fewer still offered the groups help or support in eg identifying people who might benefit from more professional input, or advised them how to refer on to more appropriate services. The groups who were most likely to do this successfully were those who had a professional support system already set up by their own initiative, either as a back-up or in the form of professional participants. Interestingly, those groups with most direct organisational professional input did not avoid these problems, but the professionals did try to control for them. Whether this had an overall good effect on the group is questionable,

as it did not allow group members to control their own group, or deal with these issues themselves.

Comparing what the participants saw as a drawback, and what professionals focussed on, it appears that the professionals had far more worries in this area than the women. The professional fears that people would deny the illness, be at different disease stages, and overwhelm people were not worries that participants had. They were more like the concerns that people seemed to have *before* they joined the group. At that time people reported being worried that they would meet individuals who were old and ill, but this was not borne out by their experience. In contrast, people in the groups felt that a mixture of participants was helpful. It may be, therefore, that the professionals' fears are similar to those of potential participants who have had no actual contact with the groups. This may reflect their relative inexperience in the area of self help.

DIFFICULTIES FOR GROUPS AS ORGANISATIONS

A further concern of professionals that emerged in the interviews was related to the group itself, not the people in it, the disease related difficulties, or the personalities involved. This included how the groups operated in practice, its organisation. These are issues that are likely to be common to many self help groups and not specifically to cancer groups.

Some of the drawbacks that relate to specific practices in groups have been mentioned in the earlier parts of this chapter. These included the implied invasion of privacy that some individuals reported, and the overwhelming help that was offered. There was also an unfounded concern that the groups were a bit "cranky" and they were in some way imposing their views on the others in the group. A consistent problem for professionals was in defining the limits of the group, and their own input. Although they made critical comments about the groups, they were unlikely to have offered solutions, and few had considered in any detail the effect of the possibility of more professional involvement.

On the more general theme of organisation, it was recognised that the groups were tackling a huge task in offering support. In one of the groups the issue of support was taken up by two or three of the professionals.

"One or two of the presently quite well members of various groups were supporting people who were far from well. And were doing a mammoth task of being at the end of a phone day and night - and going round sometimes when these people really were at the terminal stages. Yet were still denying and hanging onto the idea of self help - I'm going to get well.'"

And from another,

"These people were substitutes for the medical and nursing support - and I don't think they should ever allow themselves to be substitutes."

Defining the limits of the group was something that concerned many self help groups. The nature of the disease in these groups made it all the more pertinent. On the whole the

groups were careful not to be involved in anything that was defined as professional and in particular medical. The question again arose about the extent and the availability of services. Were women going along to a group to try and obtain support etc that was or should have been available elsewhere? Groups made themselves aware of other available services and encouraged members, and anyone making enquiries, to use them appropriately.

That group members should support one another was generally welcomed, but that the supporters themselves may need some help was recognised. Some of the professionals had taken into account that these people may not have a way of saying 'no', and that the demand that might be made on them was potentially limitless. This may be tempered by the principle of self help, that the helper is aided as much as the helped.

Professionals were also able to see that the group might have been very time consuming, and that this was a potential drawback of any group of this sort. Defining the limits of the group was therefore of paramount importance, not only for the smooth running of the group in relation to professionals but also for the well being of the members of the group. There was one instance when this concern prompted a specialist nurse to offer help to a leader in one of the self help groups. The offer was not taken up. The problems of organisation and leadership often go together. Many of the professionals were aware of this, and often had much to offer groups. They were in a position where they could not enforce that help, and found it difficult to witness problems without the power of intervention.

Groups generally had good relations with professionals. The professionals were sometimes keen to be in control of this. Some of the professionals interviewed regarded it as a drawback that there was not a professional involved in the group. They felt that a professional overseer would give the groups a degree of objectivity that they at the moment lacked.

"My advice, for what its worth, is that its a good idea to have someone like that, who is not in pain, or who is not a patient, as the whatever you call it..the convener. This gets rid of these overwhelming individuals who end up as ringleaders."

Another area that professionals were concerned about was the standard of training in the groups. Some of them had been involved in training initiatives with the groups. In particular group F had been involved with professionals on several training days, where the volunteers for the phone line learnt how to deal with calls and potentially difficult callers.

Other groups clubbed together to attend a specially arranged series of lectures. The professionals who were involved in these activities were the keenest to help the group define its limits and to help to make that acceptable to them.

One of them commented,

"I think that they ought to have some training, but we ought to be careful of the sort of training that they have because it would be nice if they had some training in listening skills and also knowing their own limitations. Y'know, when to pull out really. And on the other hand I would hate to see volunteers turned into

mini professionals, because that isn't the point! The point is to meet another ordinary woman to whom this has happened.

...I know that the Reach to Recovery (in the USA) have a very heavy program, and I think that's too much. It takes away the very value of it." medical consultant.

These very astute comments were more typical of those professionals who had been involved in training for the groups, not just come along to give a lecture to the group itself. They saw the importance of retaining the personal individual reaction, rather than a generic professionalised approach. Some groups were very aware of this, others less so. Often groups felt that they ought to have some training to validate (and legitimise) what they did.

Not many of the professionals were aware that the groups might be caught up in the difficulties of mundane matters like finding premises, money etc. For one consultant it struck him when he gave a talk to a group in an old building that was in fact being used as a health shop.

"I had a very curious encounter with them, and that always influences, y'know. I went to a totally derelict building. They had a shop, which they have now been kicked out of. They had a shop in the High Street, the Women's Health Shop. And they were being evicted because the place was unsafe. And we met on a wet evening when there was water dripping through the ceiling into a bucket in front of us. And the place was derelict, and decaying and dying, and there were these people in this room who were derelict and decaying and dying. And the whole thing was sick.

We didn't have proper seats, y'know. There were people sitting on tea chests and so on. It was so Andy Warhol. Y'know picture of these people hanging onto something - even when the building was falling around them as well as their lives. And I found that very difficult. If we'd met in a nice warm comfortable lounge it would have been completely different. So that was just bizarre. But it highlighted something for me."

Indeed the premises he was referring to had been allocated to an attempt to provide women with a "Health Shop". This had been organised by an eminent consultant, and the money available was such that the premises were not of the best. However it did provide a forum for women to find out about health and related problems, and it gave groups premises, however meagre, in which to meet. One important factor was its location, firmly in the community- in the High Street. By most accounts the project was a success, but had to be abandoned because of lack of funds. Interestingly in 1990 a similar "Health Shop" has been set up in another local community. (Scotsman 13/2/90).

Overall, many professionals made comments about the way groups were run and organised. They were concerned about the open ended-ness of the group, both in terms of access and demands on people in the group. They often felt that a professional could be involved in helping the groups deal with this, but few of them offered that assistance. Some group participants shared this concern with setting and maintaining limits, but they were less likely to see more professional involvement as a solution.

Professionals were aware that the groups might need help with their structure and dynamics, and cited examples of over-dominance in particular groups. They were also concerned that the groups received appropriate training, that this should be part of the group functioning. Some groups had developed good training relationships with professionals.

Group participants shared some of these concerns about their group. They were keen to set and maintain limits for the group, be aware of group dynamics, receive appropriate training, and develop links with professionals. However they were less likely to see more professional involvement as the solution. They were more likely to look for a different quality of involvement. They recognised their benefits as a self help group and were unwilling to compromise that.

SUMMARY: PROFESSIONAL VIEWS OF DRAWBACKS

Although professionals were forthcoming about their views on the drawbacks of the self help groups, these did not completely outweigh their advantages. All the professionals continued to respond to the groups, and in this way support them. However, the data suggest that professionals have concerns about groups that are often unfounded. This implies that even professionals involved with groups did not have enough information about them nor did they have a framework the groups fitted into. They seemed to find it difficult to accept that people acted of their own accord in attending groups. Although they acknowledged the psychosocial impact of breast disease, they were reluctant to accept that groups were sometimes the only resource for many of these women. This was less marked with professionals working 'inside' the group.

Drawbacks as seen by members and by professionals only slightly overlap. Many of the concerns voiced by the professionals are more similar to the anticipatory concerns the people said they had before entering the group. These focus on issues relating to the initial impact of cancer and meeting other cancer patients and perhaps witnessing deterioration. For most members this had ceased to be a drawback in the group, and for some the opportunity to be part of that process with other members was a function of membership.

Few professionals mentioned concerns about the practical aspects of the group, eg group size and funding. This may have been because that was not their area of expertise, although these things did concern group members. Both were concerned about the amount of possible time the group might need, and the degree of commitment and its demands on members. Some professionals were aware that they had professional boundaries of working hours etc that members might not have.

The two areas of concern shared by members and professionals alike, were those concerning the emotional aspects of cancer, and the relationship between professionals and the group. Members continued to be concerned about the amount of talking about cancer in the group. They often wanted the opportunity to talk about their experiences and sometimes did

not. Thus the group functioned to meet these needs, and at some meetings the disease was hardly mentioned at all. Professionals were more concerned that the medical aspects of treatment would become confused for people. They seldom appreciated that the group members would differentiate between individual experience and medical management. Indeed, as will be seen in the next chapter, the groups went to great lengths to regulate and control the amount of medical information in the group.

Whereas many groups wanted contact with professionals, and had considered what that relationship might entail, having both benefits and drawbacks, most professionals had assumed that more professional input would be a good thing. Professionals had not considered that their input might change the nature of the group, and that the relationship might need to be negotiated on different terms. This was most clear in their speculation about the future of self help which is discussed in the next section.

Some of the concerns mentioned by professionals were real concerns within the groups. Only a few of these professionals had spontaneously tried to help groups with the difficulties that they faced. When pressed, the most common response was more professional input, with no real consideration of by whom or how.

FUTURE DIRECTIONS FOR SELF HELP AND PROFESSIONALS

Most of the professionals interviewed made some positive comments on self help groups. This was not surprising as they were selected on the basis of their contact with the groups studied. They were, however, not without critical comments about the groups, their running and their personnel, and a few did not really know what the groups were doing. Some spontaneously offered advice about the groups or their organisation, those who did not were more directly questioned about their ideas for the future of self help and relations with professionals. It was important to find out what help or improvement professionals in contact with the groups felt that they might offer in the future.

All those interviewed envisaged that the groups would continue in some form or another. Many professionals wanted more professional involvement, few questioned the type or quality of professional input. Those professionals who were already involved closely in the group (eg the back up team of group F) made less of these sort of comments, and indicated their general satisfaction with current arrangements. The social workers in group E were unique in their attempts to make the group more "self help", and in this they mirrored those group leaders who were concerned about the level of participation in the group. These professionals wanted less professional involvement at an organisational level.

Group members varied in their views about more input from professionals, and were cautious about maintaining a degree of control. When asked about increasing professional involvement group members' typical comments were

"Ah don't think so. Ah mean comin tae speak tae us - that's all right. But as far as the runnin of the group is concerned, Ah mean, that's no...Ah mean its definitely an ex-patients thing" Mrs Farquar

"It would be too clinical. Its not a medical thing. Its more of a social night, and that might change." Carol

"No, no. Its your personal problem. All of us in the group have been through it and we've all surfaced and we enjoy life. No, nobody knows...You can't explain how you feel." Annette

Some professionals were aware that there was a balance to be struck between professional involvement and the principles of self help, while others were less aware of this issue, envisaging a support group with professional leadership. Many had not conceptualised their relations with groups as other than professional / patient. This meant that any possibility of professionals and groups working together were limited by this. A small number indicated that the groups might be part of a different approach to participatory health care, and some of them even indicated that professionals might have something to gain through contact with these groups. One oncology consultant summed up his views on self help groups.

"Its such a complex thing to have breast cancer. There's the mutilation side of it, the life threatening side of it, the cancer side of it; how other people see you, how you see other people. And personality of course...Some people like that sort of thing (self help group), and some some don't find any benefit from it - don't like that sort of thing, in fact the opposite, and keep away from it. There are people who definitely do. I don't know how you value it, what factors determine what patient ends up getting benefit from it. To evaluate self help as treatment requires a clinical trial. Unless that happens its quite difficult to deal with- referrals and such."

Although aspects of self help might be amenable to clinical assessment, this consultant was aware that, as they stood, they were not a form of clinical 'treatment'. Nevertheless he was keen for some clinical evaluation, some proof that they worked, then professionals could get involved. By comparison the groups felt, from their own experience, that the groups helped people. This was enough for them, and were keen that others should see it in this way. They argued about the choice people exerted in attending the group.

"Well, you can come and go as you want. I mean the first time I came, I thought I might not stay, but then I started chatting to M-- and it was such a relief, I wasn't the only one. That was proof enough for me."

Here was a major difficulty between professionals and groups, the benefits of self help lay in the experience of it for (most) members and in a clinical evaluation for (most) professionals. The groups were keen for the current research, because they saw it as a validation of the group, and a help for them in their relations with professionals. It was unthinkable to them that the group might get 'bad press' from the research.

Most of the professionals who were involved in an 'invited' capacity in the groups saw them as something outwith the normal services provided. They might mention another professional whom they saw as being involved in the group as a sort of link person, but it

seemed that they had not often considered the group in relation to themselves. In this way it was neither threatening to or coerced by them.

In a similar way their contact with the groups was seen as outside their work per se, but this did not always mean that they were able to drop their 'professional' roles. Some medics felt that there was no need to set constraints on the groups as they were by their nature self limiting.

"I'm sure as a doctor I should say that there are limits that they shouldn't go to.(laughs). I can't think what they are. I don't think there should be any self imposed limits. I think limits will be imposed in the group, by lack of professional expertise or knowledge. I think each group should function as it sees the needs of the group and the people involved. But there will be limits imposed on them...counselling skills don't come easy to anybody, if there's no-one whose particularly good at listening...I think limits are set by the group itself and the expertise itself."

So, when the groups stayed outwith the hospital, they could be self determining. Others felt that their experiential knowledge could be used on the wards to talk to women about their experiences. But this was to be held firmly in the hands of the nurse counsellor or ultimately the consultant. Thus the women who helped in this was were not seen as co-workers who maintained their own autonomy, but patients who were helping the consultant.

S: "Some women want to go onto the wards and talk to other women?"

NB: "We do that to a limited extent. If patients are having some additional procedure like a reconstructive procedure of the breast then we do have women in the self help group, or some of them outside the self help group who have offered to come and help. And they come and say, look I've has this op. and these are the results. Y'know, and how its affected them. And they get a little more of a realistic idea of what its going to be like after the operation, as opposed to thinking the breast will be exactly the same as the other side. So we do use patients who have had a bilateral mastectomy, or reconstruction. The more difficult side are people who are having chemotherapy..."

There was a role for women in going into the ward at the request of the consultant to talk about "additional" procedures, but apparently it was assumed that women could cope adequately, without this support for the "normal" procedure. Although the groups accepted the control the consultant might exert on the ward, they felt that they could offer help and support to many women. They were also keen to maintain the bulk of their group outwith the hospital both in timing and location. Self run self help groups saw themselves as working 'next to' the formal services. Many professionals accepted that the groups were not actually part of their service, ie they operated outwith the formal services (Kickbush 1981). Where more directive professional involvement was envisaged the professionals saw the groups as working 'within' the service. This latter model was not favoured by the groups.

It was interesting to see that the areas where it was the easiest to let the women onto the ward were those that dealt mainly with appearance and less easy where the issue might be the effects of the disease or its treatment.

"So what I would like - behind me so to speak, is a pool of volunteers. I would see the patient, and if she wanted to see a volunteer, I would pick the volunteer."

The professionals wanted the women to help and support their work in the hospital setting, which, of course was not self help at all! Most professionals in this study were aware that the groups, as they currently operated (outwith or alongside the medical setting and with primarily a social function) was fine. But where there were any initiatives to move towards a more integrative approach, the control (and responsibility) would fall to the professionals worker. This highlights the difficulties of co-operative work seen in Mantell et al (1983)

Another general view emerged about the groups themselves. Some professionals were keen that the benefits of groups could be brought under the auspices of the service that was already there.

"In a perfect world I think that, not all, but a lot of our patients would enjoy being able to discuss their problems with other patients. So I would like to offer- as part of our service- forgetting money for the moment, a system with some sort of self support system, that existed. At least introduce them to it. And if they want to test it out for themselves, then that's fine. But I think that is part of cancer care. I'd like to see it done professionally, organised, so that it was available. Again I think that you have to have it available and organised and then you can avoid this business of the odd crusader saying "Well I'm going to get 100 quid off the local church fete so we can have some coffee mugs and rent a room once a week and so on."

Thus self help principles would be used by professionals to provide a contact service for 'patients'. There was no recognition that the groups were doing something that was not being done, or indeed was likely to be done in the hospitals. The speaker above considered only the most immediate question of access and availability without questioning the nature of what was on offer. Any group that was seen to be part of the hospital and professional structure would not be a self help group, and access to it would be unlikely to be maintained on a self help basis. The groups themselves were much more aware of this than most of the professionals

Some clearly felt that a group should not take place within the hospital setting, if it did the something might be lost.

"I wouldn't advise them to be an integral part of the health service. Ehm, but I think the health service should make, for instance, facilities available for them. Y'know that if there was a group that wanted premises to meet in that sort of thing. In that way, sort of passive support. But not to have an organised, in commas clinic. But more important than that we should have more nurse counsellors.."

One professional was able to see that there might be differences and difficulties in hospital based groups.

"I think there would be a big difference in a group organised from a hospital and a group organised from the community. The point I suppose is that if a group were not attached to a body in the health service, presumable since so many of their interests are wrapped up in what is going on in the health service, there would have to be some contacts within it. It would be difficult for them to act as a pressure group too."

It appeared to be difficult for the groups to see themselves as pressure groups anyway. They, on the whole, defined their own limits outwith the main political arenas of the health service, and at the time of the study saw their role as co-operative with, not challenging, the health service and its employees. Their vulnerability limited them to areas clearly defined as personal support and experience. Thus although a few professionals felt that the groups might maximise their role alongside the formal services, they did not see that this entailed a major change in position in relation to services ie moving to a position that many would see as opposed to those services. This was something the groups went to great steps to avoid (see next chapter).

In a similar vein other ideas for the future included hospital based groups, with recognition that the medics may not be the best people to take the most prominent role.

"I'd love it (a support group) to be affiliated to us - but it has to be separate. Maybe be in our department, part of us. But I would like to see a professional person (facilitate it). Also you see doctors are hopeless. Most of us are hopeless at that. We're not good. Psychiatrists are good, they have training, are equipped and so on, and people like yourself (ie psychologists). But most doctors are appalling at it. They're far too egocentric, they want to be in the lead and start organising the thing."

These professionals see that self help has much to offer, and that it must retain some distance from the formal services to be most effective. However, they still wish to see a professional in a central, organising (and controlling) role. Although most of the groups felt that they wanted to maintain good relations with professionals, those that were firmly self help were well aware of the problems of professional involvement in a group. Some managed this by delineating clear roles for professionals as back-up expertise. Others, who attempted to integrate professionals often found that, so long as they were working in their professional capacity, they could not shed professional constraints.

"We have had several (professional) people along who really do want to be involved in the group. But, it always turns out the same. No matter how hard they try, it seems to be impossible for them to really let go of the, that control I suppose, that is so much part of their professional training. They start saying, 'Yes, but...' and then we know.... It's almost as if they cannot just let us go ahead, and stand back and let us do what we want. After all, we're the ones who are the recipients too. So if we get it wrong, it falls on us (laughs)."

One of the things that the professionals saw that the groups had to offer was help with communication. There was an increasing acknowledgement that doctors were not always communicating well with their patients. Also it was evident that people who had received medical treatment were, for whatever reason, not too good at giving feedback.

"A positive support group for patients, I think that would be fascinating. I think it would be good for patients, and I think we would learn a great deal as doctors, about how therapies effect people. And how we could improve on our purely medical approach. We could learn a lot from studying the receiving end of that. And I would do that by having someone such as a psychologist or a psychiatrist as convener. Y'know, I would have a professional person who was neutral. Obviously not a doctor who is looking after them."

Again there should be someone who was slightly apart from the experience and the treatment to be a monitor in the group. Communication was certainly a big issue for the groups, as most of their experiences (see chapter 3) had taught them how difficult it was for doctors and medial staff to communicate with them. The groups could therefore provide a forum for better understanding and communication. The group members felt this had to take place in a self help group, not in a hospital setting, there had to be some re-dress of power before reasonable open communication could begin.

Most medical professionals now acknowledge that it is particularly difficult for people who had had cancer diagnosed and treated. The uncertainty of the disease and its possibly aggressive treatment, as well as questionable outcome was recognised. The waelth of research attests to the importance that is currently attatched to psychological factors in treatment of breast disease (eg Fallowfield and Clark 1991). There was little doubt that these factors influenced both parties, and possibly made communication more difficult than with other, more straightforward, health issues.

Acting as a pressure group was something that the groups on the whole did not take up. When it was brought up in a small group, the reply was firmly that until you had been through the experience and were in the fragile situation that these women found themselves in, then you would realise that you did not upset something that you were dependent on. Many of the groups were concerned to exist alongside the health service, and they were caught up in that to the extent that challenging that service was not (at that point) on the agenda.

Where some groups did try and influence the provision of service was in areas that they felt were not predominantly medical. Thus the issues of prosthesis, swimwear etc. were predominant. They did move a little towards comment on the delivery of service in relation to prosthesis. This was a legitimate area of concern. It was challengable, and could be challenged with the support of the doctors, rather than in opposition to them. It was also something that most women still had to contend with. (Although it might be argued that there were potentially other things that they also still had to contend with in the more medical domain that they did not take issue with.) It may be that prosthesis etc were indeed seen as challengable where as the issue of communication was less so. Further it may be that at that time in the existence of the groups, it was all that they could cope with, they might in later years go on to other things.

Indeed some of the professionals had the idea that the groups should move a bit in that direction, they themselves saw things that were not alright with the delivery of service but were not themselves in a position to do much about it. For example,

"There certainly was some suspicion for some (of the group members), that medical people were eh, dissociated from the struggle and the suffering and all the complexities of daily living of these women. And that they were so concerned with their own projects and getting their statistical information that they really *did* feel like numbers, and they never were listened to or given a real opportunity to be followed through by *an* individual who was interested. Now I kind of feel they could make use of that if its a strong enough feeling, to be a pressure group in such a way that the medical profession is helped to know what kind of service *would* be useful to them." (emphasis in original)

The idea here was of feedback of useful information in such a way that it was helpful to all. Many of the groups were not confident to do this, they felt that they would be seen as trouble makers and that their health care might be compromised. Others offered something similar,

"...but (the group) may be useful in that it can tell patients, being aware that it is reasonable to criticise, there's no harm in telling what you feel."

When this comment was discussed with a small number of women in one breast cancer group, there was a fairly strong reaction.

S: "Why is it that we all see there is this need to feed back to professionals that things could be better - and yet it doesn't happen?"

V: "Well, it's alright for you, you don't have cancer. You don't have to go along to the clinic and face them when you can hardly speak because you're so scared they'll say it's back. Oh no, it's too much of a risk for us." notes

Perhaps the most interesting and observant comment was offered by a nurse counsellor who was closely involved in one of the groups.

S: "How does the group fit into the health service?"

L: "I'd like to think that it fits in as a bit of a thorn in its flesh, but maybe that's being a bit too...a bit too pushy. I would break the lever in patients' lib! I do think that we need educating as consumers of health care. And I like to think that through my association with the group and through the fact that it's very informal, ehm I can actually talk to women about the sort of things that they want from their care, and talk to them about how they can get that. How they can make the health service work better for them.

The very clear issue about this is breast reconstruction - that is the big one. So many people still think you have to get it privately. 'It wouldn't be for me.' And I can actually say, yes it can be, come on we can fight together to get it. So its not a pressure group for the health service, its nothing as exciting as that. But I do think that where it fits into the health service, it is making people a bit more aware of what their rights are."

The groups would agree that part of their role was to inform people of their rights and to support them in attaining those rights. Only a couple of the groups in this study would see

themselves as a 'thorn in the flesh' of the formal services, and then a fairly benevolent one. Indeed it was the case that the more radical professionals were far more reactionary than any of the group. It was they who wanted to challenge the process of medical care in much more overt way than the group felt possible or even stated.

The groups made additional comments about the possible role of professionals. They were much more aware that there was an issue of power and control that had to be addressed. They were determined to maintain that control. (It seemed to be a crucial factor in group readjustment that members took back control of their own lives.) However, they were keen to maintain good relations with professionals. The extent to which they went to maintain these contacts and use them are addressed in the next chapter.

The groups would have liked professionals to take an interest in the groups, and to sometimes make their expertise available to them. They differed in the extent to which they wanted involvement with a professional. Some groups (eg D and E) had what they felt was reasonably good support from individual professionals, and there was a bit of give and take in their relationship, with some group members talking about the group at medical meetings, or receiving referrals into the group from professional agencies. Others had comfortable relationships with a nurse counsellor, who seemed to provide a new layer of professional care within the groups. This seemed to suit both parties, and did not have any effect on the formal service provision.

Thus groups wanted some back up from professionals, they welcomed building up good relations with a variety of individual professionals and organisations, and were always keen to keep informed through these contacts. They also looked to professionals to inform people about the groups, but on the whole this seldom happened. This may have been due to the difficulties for professionals of evaluation and responsibility mentioned earlier.

Some groups needed help with very practical things, like premises and access to resources in general. This was something that few professionals had considered, although some were aware of the conditions under which some groups met (see previous quotes).

Overall, the groups and professionals view of their individual relations reflects a very different conceptualisation of self help in relation to formal services. Not only did many professionals feel that groups needed to be validated clinically whereas the groups did not, but they took quite differing views on the position of the group vis a vis formal services. Taking Kickbush (1981) framework of group relation to professionals, it can be seen that professionals see groups as operating 'outwith' the formal services, and on the whole define their own input to the group as outwith their own job (with the exception of the professionals working within the groups). This does not mean that the groups are working in opposition to the formal services, as in Kickbush's (1981) 'opposed to' grouping. With more proposed professional input this relationship changes and groups are seen as being 'within' the service provision, and organised and run by that service. Most of the groups aimed to work alongside or 'next to' the

services and did what they could to maintain that. This conceptualisation did not occur for most of the professionals except those who were closely involved in the running of the groups, and where they saw it as part of their function to maintain that relationship.

This in turn emphasises the conceptual difference between many professionals and group members about professional input. Many professionals who wanted more professional involvement did not see how that might affect the group and change its fundamental nature and mode of operation. The move for them from outwith the formal services to within them was seen as completely advantageous and for overall benefit. The groups, by contrast, were well aware that such a move would compromise their functioning, and along with the benefits there would be many constraints. Often they saw that the group would no longer be self help as they experienced it.

Similarly, underlying these differing viewpoints is a basic difference in the way professionals and group members generally viewed people with cancer. The former remained fairly medically orientated, and the management of the disease was primary. Group members, and some professionals, took a wider view of the potential autonomy of people with cancer and their right to make choices and act individually. In addition, group members were concerned about the social and psychological aspects of their experiences, and met to deal with that. In essence, the professionals found it very hard to let go of their sense of responsibility, while group members had started to achieve a sense of their own self reliance. This meant that the stances they took in relation to autonomy and responsibility were different. Thus the difficulties about communication between professionals and their clients/ patients was set to be negotiated from a stance that most professionals had not comprehended, and that was contrary to most of their professional training.

Whereas professionals could ignore self help groups, the groups could not, and on the whole did not want to, ignore professionals. This inequality in the relationship was obvious to group members, but less so to professionals and to previous research workers. The groups have limited choice in negotiating this relationship.

CONCLUSION

The professionals interviewed here played a variety of roles in the group, from giving a single lecture, to being involved with the groups on a regular and personal basis. However, no professional was involved in the group as an explicit part of their job - at most people had interpreted their job description to allow them time in the group. Specialist nurses and social workers were more likely to be closely involved with the groups. Specialist nurses seemed to provide a new level of primary care access for women in the group. They did not take up the women's reported difficulties of access to medical professionals in any systematic way.

All professionals interviewed indicated some benefits of the self help groups which was not surprising given the selection of the sample. Most felt that the groups offered support

and personal help to members, as well as an educational forum for professionals and patients and potentially pressure group activities.

Professionals were aware that the groups brought together people at various stages in the illness, and were concerned about this. They also expressed reservations about the emotional reactions that people might go through in the group, when people died or were ill. A further concern was that people would discuss their medical treatment and engender confusion and fear. Few took the opportunity to check out how the groups dealt with these issues.

Similarly, although professionals were concerned that people might seek out the group inappropriately, they seldom offered the groups much information, help or support in dealing with this. They were aware that there were limitations for the group and members in terms of what the group might offer and how members might be pressured by neediness in others. Most of them did not investigate how groups currently dealt with these difficulties.

Most professionals felt that the groups should become more involved with professionals, but had not considered how that might affect the group and its structures. Some, however, were aware that professionals could take over groups, and were keen to see them maintain their independence. The groups themselves were more keenly aware of these issues. Some saw the potential benefits for both in providing a good forum for addressing communication problems and facilitating information exchange. A few professionals were keen to prompt the groups to act more as pressure groups. The groups found this difficult to do, given their dependence on medical professionals for their health care.

The extent of the differences between professionals and groups in their conceptualisation of self help in relation to the formal services is seen to derive from a fundamental difference in their view of responsibility and autonomy. Whereas professionals maintain a medical approach the groups were primarily social in orientation. These together made professionals view self help groups as falling outwith service provision or else, with more professional involvement, within the formal services. The groups were not keen to oppose professionals but wanted to work next to them, being aware of the potential difficulties of more involvement with professionals.

At the time of this study most of the groups were concerned to maintain cordial relations with professionals. They went out of their way to ensure that they did not offend doctors and other medical staff. They organised and publicised the groups in such a way as to placate anxieties professionals might have. Any literature was vetted by professionals, and they persistently sought to maintain contact with professionals on a working co-operative basis, if possible, and at least as speakers in the groups. They were aware of the views that professionals had about the dangers of self help groups and sought to address that, but at the same time maintain their integrity. This was sometimes a fine balance, and will be discussed at length in the next chapter on legitimisation.

CHAPTER 7 : LEGITIMATION

“making legitimate by decree, enactment or proof; justify, serve as justification for” The Concise Oxford Dictionary

For the purposes of this work, the term legitimisation refers to the process by which groups or individuals tried to justify the groups' existence in a wider context than their immediate environment and outwith their immediate membership. The main argument in this chapter is that legitimisation was a central function of the groups, and greatly influenced the relationship between professionals and groups. Groups legitimised themselves by maintaining favourable relationships with those organisations and individuals assumed to be in positions of power and prestige. They employed a variety of strategies to define themselves and their activities in relation to the formal (usually health) services, and to co-opt favourable attitudes in prestigious individuals. It was seldom the case that this was a deliberate policy solely to win favour with professionals - much of what the groups did in this area has its own rationale of emphasis on experiential knowledge and individual information and support.

There was also a sense in which the groups needed to legitimate themselves to current and potential members, and the public as a whole. Furthermore, this process of legitimisation was an aid to potential funding, and therefore to the groups' long term existence.

The groups legitimised themselves along a variety of dimensions. Thus one of their main values as a pool of experiential knowledge was primarily a matter of internal legitimisation, ie. the group made the experiences of the individuals important and worthwhile, and the individual validated the group through the use of these experiences. The individuals not only provided the experiential basis, but by the use of this experience in the group validated both themselves and the group. The emphasis on experiential expertise as opposed to technical expertise acknowledged fears that professionals had about groups.

The group also provided a venue for receiving information, usually from professionals. This helped to confirm the group on a wider basis, as it required interaction with outside agencies. In addition the group provided a forum for interaction with professionals that was not available elsewhere.

All these aspects of group functioning were unique - nowhere else was there a social situation in which those individuals could assess and validate their own experiences. There seemed to be no other opportunity for them to gain the information that they required about cancer. Although they might have contact with professionals in a variety of settings, this was the only setting where they, and the professionals, were able to communicate more or less without the constraints of the roles of 'professional' and 'patient'. They were able to meet in locations and roles outside of medical management.

The process of legitimisation was a particularly striking aspect of group functioning as it highlighted both the interaction of the group with professionals as well as with the services. It

permeated much of what the group did, and how it did it. To this end the groups used a variety of events and activities for legitimisation in addition to other functions. Thus the groups visibly constrained the information in the groups to non-medical issues, focussing on experiential aspects and highlighting individual experience. Where groups produced leaflets they were vetted by professionals, and where a group gained funding, this served to further legitimise its functioning.

They invited a wide range of professional participation, both within the group, and also as speakers to the group, as public supporters of the group and as sources of information about the group. In this they recognised professionals' availability for involvement in self help groups. In some groups professionals also participated in training, providing a back up to the service provided in the groups. Further legitimisation came from being invited to speak at professional conferences, and then when a self help conference was set up, by inviting professional speakers there. All served to emphasise the groups' willingness to operate alongside the formal provision.

The groups' participation in this research also seemed to help them validate themselves to themselves and to professionals. Some groups were further legitimised by contact with national organisations, and with other groups. This seemed to give them a strong feeling of purpose and identity, as well as help them deal with general problems in groups.

All the group members were conscious of being representatives of the group. Many were uncertain about this and were concerned as to whether they should publicise the fact to their general practitioner or consultant. Some felt some pressure to be 'model patients' and this conflicted occasionally with their struggle for optimum health care.

Thus the groups employed all those means at their disposal to legitimise themselves. There were, in fact, very few legitimising sources available for them.

INFORMATION MANAGEMENT

One of the most striking aspects of legitimisation seeking (where it occurred) in self help groups dealing with medical issues, was how it constrained the information that was seen to be available within the group context. The groups' own newsletters/booklets/leaflets left no doubt that they did *not* give any "medical advice". Thus they made a clear distinction between this "medical" information and what they *did* offer viz. help, support, listening etc.

"We do not give medical advice, we are aware that we should not give medical advice." Vivienne

This distinction of technical and experiential knowledge was repeated in its various forms throughout the interviews and at the group meetings. It operated to emphasise to members that their experience was important. Usually women said that they did this because they were not medically trained but they were also defining the boundaries of what the group - and they as individuals within the group - should be concerned with.

The caution over medical matters was stoically maintained even where medically trained professionals were regular attenders at the group meetings and were integral to the group. It was even maintained where those individuals (usually nurse counsellors) most definitely did give medical advice, usually in the form of a reassurance, or a suggestion that the concerned individual should seek further help from a more 'legitimate', and presumably less accessible, source, eg GP, oncologist. Thus the groups acted as a first stop referral point within the health care format. Interestingly this aspect of their functioning was not given a high profile, and was not publicised. This might have been because it did, potentially, infringe on the boundaries that the groups set up in relation to 'medical issues'. The groups' leaflets might mention contact with a nurse counsellor, but her role was not elaborated on, or emphasised. Although the group was interacting positively with the formal services, indeed filtering referrals, and therefore helping in the self-care and pre-primary care of individuals, this did not seem to be recognised clearly as such. Where it was recognised, it was not seen as a forum for legitimisation. This interaction with the nurse counsellors was an area where the groups were working well alongside formal service. They were not being co-opted, and although the nurses saw their input as 'work' it was usually based on a loose interpretation of their job description.

For those people who had taken some professionally organised training, the emphasis on the definition of the limits of knowledge was further emphasised,

"You can't help over the phone on the medical side - or you're not allowed to anyway. Its like we were taught in our training; if someone says someone is loosing blood, you can't tell how much blood that is or what condition that person is in. Unless you can see the person with colour and texture of skin and all the rest of it. You can't advise over the phone, you can just get a bit panicky." Diane

Acting as a primary referral filter was unwittingly emphasised by other group members who point out that it was only with baseline information about the everyday reality of coping with the disease and as often with the treatments that one was able to make a reasonable estimate about what was and what was not "worthwhile" approaching the GP with. This important function of the groups and professionals within the groups was sadly unrecognised, because, it seemed, it transgressed the notion of what a self help group was 'supposed' to do.

On the whole medical professionals were not concerned with the "at home" difficulties people might face (ie the everyday reality of living with cancer). An attempt was made to differentiate between medical and psychosocial information, a distinction that is often blurred in real experience. But women often had difficulties in getting information and communicating with professionals that led them to seek information from groups. Thus one woman phoned up another member for information on radiotherapy as she was to have this treatment herself because of recent metastasis.

"...and she (group member) explained...I wanted to know what exactly would happen to me when I go, if I have to go to the W---. She explained, you just lie down and they mark where they want the thing. And she used to get a minute and

a half. And she said that she used to shut her eyes and count to 90 and it was finished.

But, she had had therapy after her operation, and she had to travel herself. And she was all blistered. She found it absolutely exhausting...I felt much better when I came off the phone." Mrs Unsworth

Thus the everyday reality of the treatment was put across, the strain of travelling, the marking of your body and the way that this particular woman dealt with it, by counting the seconds. The exhaustion could be seen to come from the treatment or from the travel, and even the less acceptable information about the undesirable effects were treated with reasonable equanimity. (In fact the giver of the information suffered extremely painful blistering but was obviously careful not to emphasis this - perhaps an example of editing information and protecting the medical profession as well as emphasising that the group did not deal in scary stories.)

Despite the none too rosy picture Mrs Unsworth, the caller, still found that it made her feel "much better". Perhaps the interaction itself was more important than its content. There seemed to be no other available source of this information, or perhaps this interaction. Professionals *might* supply a technical account, not an account of the experience. The women, unlike medical professionals, did not make a major (and false) distinction between the physical and psychological aspects of cancer and its treatment.

In a similar way much information was passed on in the groups with people colluding to share their experience (edited or not). This type of information was highly valued in the group. There was hardly an individual involved in the study who did not make it a point of reference. What did differ was the amount of emphasis placed upon it and the frequency with which such exchanges were seen to happen and its desirability.

Experiential knowledge was seen as a unique contribution,

"People, they don't know how you feel when you are told. Well, its like anything else, if you haven't experienced it you don't know." Lena

and

"Its no use talking to anybody else about it because they just don't understand...I feel that about mastectomy. Until you talk to someone who *knows* about it, whose had the same thing done, the person you're talking to hasn't a clue. They can say 'Oh yes, I think I know' but in fact they don't." Wilma

It was also apparent that this experiential knowledge was an essential part of most exchanges and that this made the roles of the giver and receiver more flexible both within that interaction and through time. Thus the group situation allowed women to move away from feeling powerless in interactions, as they clearly did within the powerful structure of the health service. In this sense the group validated the women's experiences, as well as using the uniqueness of those experiences to consolidate the group.

Thus being in the group

"...has a unique appeal - somebody who has gone through the experience...there is a difference in autonomy. There is no client relationship, in fact they are very anti this in the group. Not only is there no client relationship, they also do not accept the cancer model. It is seen as a cop out. And that certainly is one point of view." Social worker

It seemed that although the information exchanged was essentially limited to non medical topics and related to personal experience, the underlying assumptions remained challenging to the medical models which emphasised the biological aspects. In a similar way cancer itself seemed to highlight the difficulties with a strict medical model, an illness with no known cure, and the apparent importance of psychosocial and geographical factors. The groups were concerned with the overall effects of the disease, its onset and its treatment on the lives of people. The quality of life was as important as the number of years lived, and it was not simply a matter of biological survival. They recognised the physical aspects of cancer, not only in terms of life as survival but also as life lived. The physical constraints might mean difficulty in reaching a high shelf, or avoiding minor injury to a swollen arm. For the groups the emphasis lay in the psychological and social aspects - of how you might share your experiences in order to make sense of them and learn to put the most used objects on the lower shelves in the office, or wear gloves when gardening.

Somehow this change of emphasis away from the purely medical aspects of the disease challenged the limited view often taken by the medical profession. Those individuals in the profession who did recognise these other aspects of cancer were working in a system that, on the whole, did not allow them to address it. Those who wish to do so, had to do it in their own time, and through another medium, like the self help group (see for example Weir, Dean and Calman 1984). In more recent years there had been an increasing awareness and understanding of the psychological difficulties that women with cancer face, and this is reviewed by Hall and Fallowfield (1989). However it is less clear how much practice has changed, and efforts to employ nurse counsellors does not seem to have been matched by suitable training and support for them (Roberts and Fallowfield 1990).

Within the group medical or 'dangerous' information was somewhat restrained by the very fact of recognition of individuality.

"You can share your experiences with other people, and see how they feel about things. Nobody's, eh, case is exactly the same as yours. You never come across the same kind of case as yours. I feel that mine was badly managed from the start..." Lynda.

Any implied criticism then was one of individual management etc. and did not collude with any other to form a coherent criticism of any profession. This might have been (yet another) reason why the groups were, on the whole, reluctant to act as or see themselves as a pressure group. This is sometimes seen as a 'legitimate' role for them (usually by

professionals, who felt themselves constrained by their professional role). The use of the word 'case' is an interesting legitimisation procedure, but one where the individual is colluding with medical terminology.

Information was from an individual point of view and was thus neutralised or detoxified. The emphasis on individual experience was taken to its logical(?) conclusion and specialisations develop and limits were set on interactions, so that people were, in some way 'matched up' in terms of experience.

"(name) is very good, would be good for someone whose had chemotherapy...because she's been through it, and I couldn't *begin* to tell anyone what its like or even begin to sympathise. All I would know is that from my own point of view it would be terrifying. But I couldn't sit there and give anyone any comfort and reassurance because I have no idea. And you really do have to go through these things to justify the sympathy that you've got to give someone else, and the understanding. That's why the medical profession is very very good (with technicalities) but you have to go through something to know how much it hurts inside." Lena

To a great extent the less controllable "nattering" that went on was regulated to occur between people who had been or were about to go through similar experiences anyway. It was remarkable, in fact, in some of the groups how little individuals knew about each other, sometimes not even knowing that they had had similar treatments etc. The possibility of spreading "scary stories" was limited and on the whole that was left up to the professional speakers. Thus the group was legitimising itself through the control and limitation of information.

Underlying this passing on of information was the assumption that on the whole it was "good to talk about it" and that

"You draw them out on their illness because they really do want to talk about it. I think that the fact that they know you've had it helps. They feel that they are not alone in the world, because everyone thinks that they are the only one that has had it." Ursula

So the therapeutic talking was used to reduce feelings of isolation (and associated stigma) and to allow therapeutic "release", or catharsis.

The information value in this type of talking was minimal. The focus was on the feelings, interaction and the roles (again interchangeable, at least in theory) played.

"You can talk about that sort of thing, about cancer and that, where you wouldn't feel like maybe talking about it in front of another group of people who may have nothing to do with it. It can bring it all out. Its brought out into the open which I think is a good thing." Mat

Its not that people did not talk in other forums but this one was special. The group was an appropriate place to talk about your experiences. It also offered each person the chance to be both a helper and helped.

It was strikingly clear that people had different ideas about how much information they wanted and about how much they wanted to or did talk about cancer or related topics. Some people saw this as the main function of the group while other members, often in the same group, saw this as of intermittent but maybe underlying importance. Within the groups some people saw an over emphasis on cancer as a drawback, and most recognised that it needed to be controlled and not overwhelming. It was most common for people to talk in twos, or in small groups. Full group discussions were often prompted by other things, like radio and TV programs (which were seen as sources of information to be treated cautiously - with good cause); articles in newspapers etc or books. It was quite rare for a group discussion on experience or treatment to arise, and rarer still, in many groups, for it to be scheduled. Most general discussion was on 'safe' topics, like bras and prosthesis, ie legitimate topics. But the major initiator of any cancer related discussion was a speaker who was usually a professional.

"Its only if you have a speaker who is talking about mastectomies that you tend to say what your experience was...and did they mention cancer which of course very few of them do (at diagnosis)." Kirsty

The same woman remarked,

"I wouldn't go if that were the case. I wouldn't want to be reminded of this. Its basically social (the group), but if you want help its there." Kirsty

Another member of the same group reiterated this point of view,

"You don't want to talk about it all the time. You get fed up listening to lectures on it too." Irma

Thus fears that medics had about the dangers of information on the scary aspects of cancer were avoided. In some cases it was apparent people reach a saturation point, they wanted not only to be able to talk about cancer, but also to be able to talk about other things in their lives. The programs of some of the groups took this into consideration.

"I thought it would be a discussion among the ladies about how they felt and what had happened. And that is how it is. And sometimes they don't refer to it very much because I think-well you know so much about it yourself and what has happened. You just try and have a nice friendly discussion." Mrs Unsworth

The information in discussions was seen as quite different from that of speakers. Information that came from speakers, as well as what was talked about while they were party to it, was not monitored in the same way. There also seemed to be a distinction between what the group discussed as a group, which was highly vetted (by themselves) and what individuals talked about together, which was less controlled. If questions seemed to be arising in the group, they were likely to invite a speaker to talk about that topic. This effectively managed the information, and allowed women to receive information 'at a distance'.

Sometimes people were concerned about aspects of their own lives and the operation of their own bodies (reduction of self control and confidence in health matters seemed to be

affect of the sudden diagnosis and dramatic effects of treatment). Part of this was the fear that having had cancer anything subsequent could be a potential metastasis. This was taken as both normal and "neurotic" within the group.

Basic everyday type of information about the experience of cancer was lacking and women had no other source of such information in the medical, or any other social system. They were all well aware of the the "busy GP", and repeatedly said that they did not want to infringe on medical time, without good reason.

This created a dilemma, so that the lack of confidence in themselves interacted with a repeated fear of metastasis, with blocked access to expertise from a medical source. This made the information available in the group even more valuable. The group approach also seemed to encourage women to think for themselves, rather than to blindly seek reassurance.

"Yes. People do sit around and talk about their experience, more about what has helped than their experience. There are small things that still worry you a bit. You don't want to keep on asking silly things." Vivienne

"...then you have your pains, and you have this that and the other, and you don't know if its right or wrong, or should you use your arm or should you be doing this or that? So I asked her (a friend who had had 'the operation' 20 years ago) to come round. And I said 'You probably don't remember what happened' and she said 'I can remember every minute of it.'" Chrissie

So what was not even regarded as information in a medical sense was extremely important for the individual who had to cope with arbitrary pains and aches and illness in the shadow of possible recurrence. So much so that the memory was an abiding one.

The possession of this pool of information and the process of putting the disease in its place in everyday life was an important function of the group, and one in which all members who have had the illness could take part. As time went on the women began to regain some confidence that they were not abnormal in having these worries, and that many of the things that triggered the worries had concerned other people too, and were a normal part of readjustment and recovery.

This was something that professionals were not able to do, not only because they didn't have the experience but also because they did not have the time or the access to that type of information. It was also questionable whether they were the right people to do it anyway. It was also possible that professionals regarded this type of information and reassurance as too "blanket" and that "real" problems (ie medical rather than psychological or social) may be missed and certainly that could have been the case.

Groups coped variously with this. In those where there was a professional person intrinsic to the group, usually a nurse, she would look at lumps and swellings etc. and reassure or refer on. But in those groups where there was no possibility of this the general strategy seemed to be to enable that person to seek medical help by recognising their need for information. The underlying assumption being that if it was causing that amount of concern

then it required attention of some sort. There was some evidence that women over monitored themselves in the initial period after treatment. Most of their worries were dealt with in the group, where at least they had an idea of what was a general experience. This also seemed to help with the problems of communicating within the medical setting, as people became more certain of themselves.

Similarly by defining this sort of information as everyday and experiential the group maintained its control over it. It was clouded by jargon, although they did familiarise themselves with medical words.

"Well this thing with professionals (about counselling fears). I think that a lot of the time you will really be talking about quite ordinary things. They do not really know how bad it is. (Anaesthetist) did not know how someone could react so badly to anaesthetic till he saw me. There are a lot of things about which you wouldn't care normally...with this no-one tells you that you will feel this discomfort that is sort of painful for so long. Its not too bad, but I always think "What about if someone grabs my arm?" Annette

The division between what was regarded as lay and what was professional knowledge was quite apparent.

At this point it is perhaps worthwhile indicating two significant overlaps in information. One member remarked after a particularly difficult talk (full of medical facts) from a consultant surgeon,

"I found that after I had the operation that all my ideas about cancer were just layman's (sic) knowledge. I had no professional knowledge at all. And a lot of them were probably old wives tales (sic). And things that I thought were... so - along comes Dr B shoots the whole lot down. It did impress me and it was necessary and I was glad of it in a way. Ignorance is bliss - I suppose that is true too in a way." Clara

The ability of the group to cope with medical "facts" could be seen as another way in which it strengthened its status with the medical speaker. However, it also inadvertently reinforced the speaker in ignoring the emotional aspects of cancer.

This factual information, as well as experiential information, was not readily available to people who had had cancer diagnosed. The importance of well communicated and relevant information was emphasised. The groups attempted to inform themselves from well known and recognised sources. Currently the self help groups seemed to be the main source, for many individuals. This could possibly change with the employment of more nurse counsellors, who interestingly did some of their work through the groups. They may have been gaining support and validation as well as offering it to the group. Further research in this area would be welcomed.

The group members learnt to deal with medical information about the disease and subsequently about their own prognosis and life. They would often seek out this information, some of which may be very difficult for them to handle emotionally.

Professionals sometimes found information about themselves in a group very difficult to accept. A few people in some of the groups not only continued to work as professionals in the area when they themselves had cancer but also attended group meetings. Comments from them indicated how difficult they found the everyday information of the experience of the illness.

"I always believed that I knew what people felt like and was able to help. But going through it myself it was apparent that I did not. I've come to realise the huge gulf between professionals and patients - the telling them what to do and how far away it may be from where you are. Part of the point of the group is to lessen this gulf. So those who shun the establishment do not do this, they widen it."
Social worker

Professionals who did not take up the opportunities for contacts with the groups were missing out on a learning experience, painful though that might have been. The fact that the groups could provide an environment for the supply of information from and for professionals added to its sense of validity. When professionals recognised the group as a source of information for them the groups were reinforced in their attempts to deal with the experience of cancer.

This also served to indicate another source of legitimisation, contact with professionals and being seen to stay within the established dogma. It appeared that generally speaking the group did not feel that they had any option in seeking legitimisation. It was very much a case of do or die, in fact not dissimilar to the amount of option that most of them felt about their treatment.

The groups sought out information and were seen to be doing so. They asked for speakers and they went to the hospitals for on the spot information. This was a public display of their willingness to accept the professionals as sources of information, and to fit in to the system, ie work 'next to' formal services. It also worked to further legitimise the group and what it was doing by giving it a visible (and subservient) profile.

This seeking out of professional information on illness and treatment was somewhat out of line with the overall emphasis on the importance of personal experience. But there was an underlying assumption that members ought to be "up" in the latest developments. Individuals had options to select themselves into or out of this. Members were not obliged to attend any meeting and could filter out those which covered topics they found difficult. Some professionals were aware that the value of the groups lay in support and sharing, and were keen that they should not become "mini-professionals" (see page 176-7)

Thus the groups set themselves up to deal with non-medical aspects of cancer diagnosis and treatment. They were careful to define the limits of their knowledge, and perhaps in doing so were acquiescent. Where they had some training, this served to emphasise this boundary even further. They concentrated on the everyday aspects of living through cancer, and the shared experience of it, which was of major importance to the members, as

well as a source of validation for them. They placed great value on therapeutic 'nattering', but they were careful to edit even this information. They individualised it and thus 'detoxified' it in terms of any coherent challenge to the services. It might be argued that in an effort to legitimise the groups, they sometimes missed opportunities to challenge and inform professionals about emotional issues.

Group discussion of treatment was relatively rare, often taking place when there was a medical expert around. They sought to inform themselves of current medical opinion from medical sources, eg by inviting known experts. They made a strong distinction between technical and experiential expertise, and were helped when professionals also recognised this.

PROFESSIONAL CONTACT

Along with the constraints that they put on the information that was available through them, the groups legitimised themselves through their contact and interactions with local professionals. Posner (1989) suggests the narrow line that groups must follow.

"While many of these groups can be seen as constituting a challenge to the bio-technical emphasis of medicine because of their focus on and development of, expertise in other aspects of health care, at the same time they often reinforce society values by borrowing status from the prestige of the official medical profession."

Whether the groups actually had any real choice in this is arguable. They existed in a world dominated by professionals, and generally remained under their medical care. All the groups had some sort of contact with professional people in their locale, and they sought out this contact. No group chose to exist in isolation from the available services, but they all had different patterns of interaction that seemed to evolve and change over time.

Where professionals were involved in the organisation and running of the group, it seemed that the members of the group were less concerned about legitimisation. That was the concern of the professionals. The main example of this is group E which was started and continued to be run by social workers. The general opinion of the women in the group was that both the social workers and mastectomy nurse provided some sort of legitimisation for them- the group was set up by social workers and they took time to organise it, provide accommodation etc.

This legitimisation was not always seen as going one way or being entirely without cost.

"It's their baby type of thing. They don't want to be running the group. But they are the ones that have to be the mainstay through, because of people coming and going so quickly. It needs that steady part, especially with M (mastectomy nurse). But they want the members to be involved." Tessa

There is an assumption that professional workers got some sort of status out of having this "baby". Indeed it seemed from the documentation of this group that it had been welcomed as a development by senior social workers. The group had now begun to make demands on the

professional workers that they did not want and in response they were trying to make the members more responsible for running the group.

The members saw the social workers as professionals who knew about groups and how to run them so it was acceptable and also credible that they did so and continued to do so. The group was thus both internally and externally validated by the professionals. There was some anxiety and dependency expressed at the thought that the professionals were pushing the group towards functioning on its own or with less professional involvement - but this tended to be expressed on a practical level with reference to the perceived status of the group in the eyes of other professionals.

O: "They are in a position to go and talk to people and say "Could you come?" or write to them from a professional point of view, y'know, rather than 'We are a self help group would you like to come and talk to us?"

S: "Do you think they wouldn't if you wrote that?"

O: (Hesitantly) "They probably would, but I think its easier, y'know, the old boy network if you like. Its much easier for them to ring up or write when they know them." Olive

Quite clearly the women in the group were reluctant to give up the status that the professionals endowed. They had never had to address the question of legitimising themselves or of presenting themselves as a valuable and acceptable group. (The women in the group were not unaware of the conflicts within the hospital about the existence of the group.)

"The king pin is your social worker, obviously. Y'know because they are professionals... obviously they are professionals and they know how to run a group y'know." Chris

Thus the social work presence was seen to act as a rejoinder to possible criticisms and proved that the group was well run under the aegis of the social worker department and constantly monitored medically by the presence of a nurse. The professionals legitimised the group framework and the members were happy to operate within that and were reluctant to change.

Generally the members had never had to face the question of legitimation in a way that other groups maybe had. Because the group was set up within a professional context by professional people any question about the validity or usefulness of the group was dealt with by those professionals and usually in their professional capacity. The issues of access, premises, funding etc were all dealt with primarily by the social worker and nurse. Any query about whether or not it was a legitimate platform for a medical professional speaker was dealt with in a similar way.

So in one sense the issue of legitimation was less of a concern for individual members of this group but more of an issue for the professional workers. They did in fact attempt to confer some sense of legitimation in the first instance by getting the group "evaluated" which

was generally resisted by the women and never completed. (Participants were asked to complete a short questionnaire on the group when it was first set up - these were never adequately completed or analysed.) However the group was never wholly run by members, and there were suggestions that professionals may legitimise a group at the expense of its self help functioning.

Another group (group C) had been set up by a specialist nurse who had worked persistently at establishing the group as self help with some support from her. There was a strong committee, and the group appeared to be only moderately concerned about issues of legitimisation. Indeed they sometimes rebelled against their parent body (the local breast association.)

"They asked for two people to sit on the committee, and off ours the two they had in mind were (name) and I. We both agreed not to get involved but we eventually had to agree. So now we do it." Bessie

This could be seen as biting the hand that legitimises you. The group members had obviously weighed up the personal cost and the group benefit and decided that it was not worth it. But they were not allowed to opt out so easily. And they were aware of why.

"The Breast Association see the group very much as their baby. But its quite different...they don't really have very much to do with (the group)." Sonya

So they were not unaware of the price that had to be paid to be legitimised, and they were obviously concerned about issues of control and status.

These examples of professional involvement highlight differences in legitimisation, that seem to be associated with professional involvement. Both could assume input from recognised professionals as a matter of course. To some extent the professionals continued to work within their professional mode in each of these groups, but with greater flexibility in the group C. This was not the case in other groups.

In other groups members remarked how difficult it was for professionals to leave their professional "status" behind and to accept being another person in the group with some expertise in some areas. They emphasised that the professionals were no different from any other member of the group.

Many groups did bow to the need for legitimisation, but did it with their "eyes wide open".

"It is very difficult to get professionals to get rid of their professional framework. They come in, and its really hard work, because we are not used to that, at least not in the group. No-one assumed they have the answers for anyone else. And even if you take something like co-counselling, even that makes an assumption the one person is a 'counsellor' while the other is.. well client or patient I suppose you'd call it. In (group D) we're trying to get away from that." Sarah

This exemplifies the difficulties that the groups faced in not only changing their own status but the expectations of professionals. The professionals were a part of legitimating this

group, but the members still tried to maintain the control and mode of interaction that they found suited them. They were reluctant to give that up. This contrasts with some other groups who seemed to put aside their self help ideologies when professionals were present. Other groups (with the exception of group F) did not have such a well thought out and articulated stance in relation to professionals.

Perhaps because of this, group D had strong relations with a variety of professionals in hospital, social work and in the hospice. Relations were fairly egalitarian, with a sense that differing expertise was being shared. They were also more likely to receive referrals than other groups. They had managed to legitimise the group without bending their self help principles too far.

The groups with less direct professional involvement did have to work harder at representing themselves to local professionals, they held the responsibility for that themselves, it was not overtly shared with a professional. The groups therefore continued to legitimise themselves wherever they could. Even those groups with high professional involvement continued to justify the group. There were many ways of displaying/encouraging/allowing a notion of involvement with professionals as a means of legitimising the group.

One method that involved little real active element (at least on the part of the professional) was the use of the name of an eminent professional as the "patron" or "honorary chair" or titled head of the group.

It seemed to be generally agreed that names mattered. As a technique to gain general recognition and approval it was one of the most useful. Thus most of the literature that was used by the groups that was to be used as publicity or propaganda has an eminent name or the professional in the group mentioned somewhere. This on the whole was seen within the group for what it was - a token in the game that had to be played.

"We personally are not interested in having standing as a group, but unfortunately you need it. Its like life, you need certain people. And if you have a chairman that does nothing, but is well known, he's got a big name...you think 'yes', because you think, well trust is the wrong word but something like that."
Jeanette

And this use of names was something that the professionals acquiesce in so that

"The (D) group have me as one of the professional people involved, just as a name. I presume to give it the authority of, of professional authority. But I'm not in the forward of the organisation of it, or (group A), apart from a little fund raising event at the beginning." Nurse counsellor

So it would seem that in some sense the professionals only had to invest a small amount of time and energy in it to reap great reward - for the group and sometimes for themselves.

(It is interesting to note that the quote above is from the "sister" mentioned in the quote by Ethel (see page 210). This "sister" did in fact feel that she had done very little in the groups

yet it was apparent that her input was highly valued and seen as much more than she gave it credit for).

Similarly names were used again and again during the interviews, particularly those with group members who seemed to want to legitimise the group within the research. It was apparent that those members who had been involved in any sort of publicity interview used this technique, and quite often managed to mention several hospitals and related staff members in the area.

Fairly typical for most group members was some idea of the professional involved as "names" but a less clear idea of their actual contact or connection with the group.

"There's, I don't know how much they are involved but there's quite a few of their names on the booklet, like the Bishop, and one or two MP's I think. I think Prof T--, he's come and spoke, hasn't he? Prof G--, oh Prof G-- hasn't spoken at a meeting but he's involved in it. And quite a number of people have been concerned with getting funds, y'know." Ailsa

So this type of legitimisation by name included people of "standing" (like MP's) as well as cancer/health experts. It was particularly useful when applying for money.

"It also helps now its a charitable group, because names help with that. We managed without money y'know up until..." Ursula

The use of these "names" was seen as an indication of support (that those people allowed their status to be thus exhibited in relation to a self help enterprise) and in and of itself gave status to the group in the eyes of the outside world. This was not seen as entirely without its difficulties though and often members had a very clear notion of what they were doing, viz bowing to and having to collude in a world where these sort of techniques work - whereas their own basic philosophy might be quite different.

"I've been lobbying for money, and I do it. Although in reality I know the danger of this awful take over. I've said we've got a nurse and two doctors on my committee. You have to really- so long as you are aware of it. And what can you do about it?" Sarah

In an ideal world, no doubt, this sort of legitimisation would not be necessary as the group would be seen to be valued as and for itself and not the number of medical professionals it could boast.

The position for the groups was also a tentative one - because the power relationship was seen from a general point of view as one way ie from the professional to the group, and not prestige gained by the professional from the liaison. This may not have been entirely the case. Self help is increasingly being seen a "legitimate" area in and of itself. Jacobs and Goodman (1989) suggest that expanded professional consultation is an expected outgrowth of legitimisation of the self help model.

On the whole groups saw themselves as having to tread warily to maintain professional support, to define themselves as being within acceptable parameters (not transgressing the boundaries and rules).

"So far the group has been supported by the (medical) profession and has close contacts with quite a few of them. In the training scheme (consultant psychiatrist) and (nurse counsellor) are involved. The group has had quite a few letters of support and eight or nine of them were submitted with the application to the council for a grant. Amongst our supporters are the local medical Committee. We have been very lucky as we have not yet run across the path of a consultant." Mat

So although the group may have from acceptable to excellent relations (from their point of view) with professionals they were aware that they earned this and it could be endangered quite quickly.

Apart from allowing their names to be used, professionals outside the main group structure might interact with the groups in a wide variety of ways. When asked about the groups relations with professionals one group member replied.

"Well, that's very good really. Somebody like (nurse counsellor), well she seems to be move between the professional and the group very very competently. And the people who have been to speak to us, they've been very very helpful.

And I think Prof G-- appreciates what the group is trying to do. Which is a good thing and we have a good relationship with him.

These people who are coming to talk to us, Mr D-- (consultant surgeon) and Dr S-- (Radiologist) I think that its an indication that its a good relationship that they would give up time and come and talk." Celia

Without exception, and despite organisational differences, all the groups in the study would invite known medical professionals to talk at the meetings. Thus covering two aims; one explicit, the informing of themselves about the illness and its consequences, and secondly acquiring legitimisation overtly - the presence of a local expert, and covertly by grounding their medical information in a fully legitimate source so that members could refer back to it as coming from a doctor. The programs of the groups were printed and distributed on a regular basis, and so the names of those giving talks were seen on this. So in addition to the name of the honorary chair, the names of actual speakers were connected to the groups.

Groups saw the meetings as a means of acquiring information, but often saw them as a forum for the exchange of information, and on rare occasions for airing their own views. On the whole professionals came into the groups and presented reasonable and informative talks and the group members put questions to them. Often the same speakers would be asked back again, and a reasonably comfortable relationship was set up over time.

"We get inclined to have similar talks each year. They start off being similar but they never turn out to be the same - because different people are there and different questions are asked. and you get quite a different outlook.

Dr C-- (surgeon) has given two now, and they've been quite different in fact although the basis is the same. The actual meeting has turned into something different.

And we've had this clinical psychologist, he's very good. Surprising, three men! And they seem to love it too." Clara

This indicated several aspects of interactions with professionals that existed across the groups, ie selection from different levels of the medical and para-medical profession, the dynamics of the meetings and the responses of the speakers. In terms of seeking legitimation the groups could be seen to be biased to several sections of what might be called the "power holders".

It may be significant that they were usually men and the repeated visits of speakers, which could be construed as continuous support (therefore legitimation at two levels) also allowed a degree of familiarity with these individuals which de-intensified the power relationship. In some sense both were forced into regarding the other as human.

Sometimes the groups had no knowledge of the internal rivalry or co-operation amongst professionals. They would occasionally mention other speakers to a professional that they were inviting to the group. This often worked well for them and indeed one speaker commented that his judgement of the group was partly based on the connection with the professor.

The fact that hospital clinics or general practitioner's surgeries displayed posters, or the group's leaflet, condoned and validated the activities of the group. Allowing publicity in this way did not imply that the general practitioner had any realistic notion of the group or that the hospital as a whole had a benevolent attitude towards the group. This meant that the group sometimes received unsatisfactory referrals (unsatisfactory for all concerned) but these were remarkably tolerated.

Professionals occasionally acted as referrers into the group, although this was by no means unproblematic. Group members who have a high organisational profile said,

"We get patients from (hospital) and (breast unit)." Vivienne

and,

"We get sent patients from Dr P--- and they've been quite a few come from (hospital)...." Sarah

The most straightforward professional referral into the group was that done by those who had enough contact with the group to have a reasonably realistic idea about it and who also were in a position where they had access to or contact with people who might want to have information about the group. Mostly groups "got people" by a wide variety of means (see chapter 3). Professional telling people about the group was seen as another source of

legitimation, because it frequently required access to or at the least non-conflict with professional medical sources.

Referral directly into the group was seen as an achievement with the notable exception of group D who said that they had not sought referrals in this way. They probably had the most consistent pattern of professional referrals into the group. This related to a number of aspects of the group, but mainly what might be seen as an inappropriate referral into any of the other groups was acceptable by group D. It was not only more generic in membership, but also extended its remit beyond providing support for the generally well, to helping people face death and dying.

Referrals were seen as gained by an acknowledgement of the outstanding qualities of the group (relatively rarely expressed),

"One or two people come by word of mouth, and then one or two people come from L-- hospital. Because the other three members of the group had mastectomies and had connections there. And there seems to be some feeling that this wellness comes from the group." Celia

So even though the qualities of the group were involved, it was actually individual members who had "contact" with the hospital (usually because of continued health monitoring). Also it was not the hospital which referred, but usually one or two individuals within the hospital. There was no question of a coherent policy towards the group(s), only an individualistic approach. (This appeared to be changing around the time of writing.)

Thus referrals came through a small number of individuals in a locality because they personally have come to see the value of the group. Those professionals were then seen within that role, as a group referrer, and consequently a legitimator.

S: "Do you get people referred on then?"

Mrs F: "Yes, they do now. But they never did. That was a very big breakthrough. Ah think it was thro Dr S-- who was responsible for that." Mrs Farquar

So having managed to gain the approval of one individual then this person might act as an enabler for the group in other circumstances.

Groups were occasionally approached by local professionals for information

"We've had quite a few (phone calls) from social workers, on, well mostly wanting money. Because they can't get it, can't seem to. Y'know it will be for paying a telephone bill or something like that...well we can't give them money for that - because we don't have enough money for that. But what we do say to them is contact Cancer Relief because we think they would probably help them. But they (social worker's) should know that.

Mind you we found that quite a few doctors don't know about it. Fancy that eh? We could actually tell them something they didn't know!" Ethel

The group benefited from a view of itself as a source of information for experts.

Thus the groups were able to use their various contacts with professionals to help place the group in relation to the formal services and to legitimise the group. Thus where professionals held organisational positions in the group, group members seemed to feel less need for legitimisation. The groups' relation to professionals was already defined by the organisational role professionals already played. In other groups, with a stronger self help identity and organisation, legitimisation was a concern. They used any contact with professionals to highlight their good relations and their position of working 'next to' the formal services. Thus where professionals in the highest positions of prestige were used to legitimise the groups through being a 'name' in the groups' program and part of their public presentation. Professional referrers and speakers also helped legitimise the group. Overall, the process of legitimisation through interaction with and publicity about contact with professionals seemed to work well.

MEMBERS AS REPRESENTATIVES

Several group members mentioned their awareness of representing their group. They were very cautious about this and were concerned that the professionals they were involved with might be critical of the group. Some were 'scared' to mention that they attended a self help group in case the professionals disagreed with groups. At the same time they felt that they should mention that the group helped them.

"Its a bit funny when I go for a check up at the hospital. When he says to me 'you're looking well - and how is your husband' I feel like saying to him, its not my husband who has helped so much as the group. Well (husband) has helped in his own way, but..its different at the group. I sometimes think that I'll tell (GP) and then I wonder - will he think I wasn't coping or something, or maybe he thinks the group is cranky ? I'm quite a coward you know. But other women say the same..." Kirsty

So being seen as part of a self help group has its dilemmas for women. They still worry about compromising their relations with health care professionals. Other women were more open about their involvement in the group, and used their own experience to legitimise the group to professionals and family. Mainly these women had been in the group for some time, and were involved in some form of organisational role. Many women were pleased that 'their' consultant had been to the group, and would take the opportunity of mentioning this at check ups etc. They were thus able to validate the group, once they felt safe in representing the group to professionals.

PUBLICITY

The groups were helped when they received any good publicity. This happened to several of the groups, being invited to speak on a TV program, or radio show. This also helped them promote the group, and encouraged new members.

The legitimising function of publicity was particularly powerful if it was associated with professionals. Group D in particular seemed to experience this sort of legitimisation, or at least expressed it more frequently.

"Sarah and I have been invited to (the hospice) on Friday. Dr H-- suggested we talk with Dr C--, his assistant, so we have an on-going thing with (the hospice). And he also thought that we could learn from his matron about the development of a home." Nina

Again an individual decision not essentially a policy but the impression was definitely of cooperation and partnership rather than condescension.

Groups or individuals within them were not infrequently approached to give information about the group to a professional audience.

"Mat and myself were invited there (oncology dept) to tell them a bit about (the group). And they were amazed when we told them about (the group). And now they've invited us back... They've also written to the council for us - given us terrific support there... P-- (a general practitioner) got in touch with the General Practitioner Council committee and they sent letters of recommendation to the town hall." Jeanette

The groups were keen to promote an accurate image of the group, and at the same time legitimise the group.

FUNDING

Supporting the group might take a more tangible form occasionally, like the direct provision of funds or the support of applications to potential funders. For some groups this did not arise as an issue, and certainly in the first instance they often required little money. But as the groups grew and changed and the scope of what they did developed then often some source of income was needed. Attached to the predominant concern to get money to support the running of the group were less obvious aspects that were to do with legitimisation.

"Now prof. G--, as you know, has put his own money into starting the organisation, and he was willing to do that in '79. Then, of course, it all fell through." Vivienne

Strictly speaking if this statement is compared to "objective fact" it was not true, but it worked well as a legitimising mechanism. It operated on several levels. The professor was seen to be using *his own* money to fund a self help group, but was also apparently willing to use it to support self help generally (ie as a principle). Moreover he was going to support this particular group as it, unlike the one in 1979 has not failed. It had proved itself.

The money that the professor gave the group was certainly not his own personal money, it was money in a fund that he had control over. Nor was the money to get the group started at all. The binding element of the funding was that the group should exist for 12 months before the money was donated. This faced one of the prevalent criticisms of self help groups, viz that they are transient and therefore not worth funding, especially in the light of the earlier

group floundering (fortunately not principally through direct lack of funds - for the clear conscience of the professor). This type of restriction on the funding of new enterprises was quite prevalent and the basic philosophy followed in this place was not unlike the process for 'urban aid grants'.

To receive any sort of money was seen as legitimising. One group member made the astute observation when asked about this,

"If people are valued in money terms in a capitalist society - and someone gives you money, then you are worth something. You may not like it, but that's how it is." Earnest

perhaps little more needs to be said than the irony that this statement conveys.

Money was given if you were seen as "worth it", but groups were clever enough to realize that it was often a case of who supported your application as much as anything else (if you were applying to a funding body that recognised conventional values). It may be a severe blow to find that the limited resource, say of council grants, had been given to those, who in the opinion of the group were far less "worthy".

"Imagine not giving us the money, with all those letters and all? And do you know who got it? A bunch of lesbians. Eh, well, a bunch of lesbians. What do they need it for?" Heather

One group was approached by the social work dept, firstly to put in an application for funds and then to extend to an area outside the city.

"We have been asked to go to M--(nearby town). It was the social work department that asked us to go (there). Because of the known need. We have in many cases not wanted to expand at this time." Nina

The group was not entirely naive about the motivations behind these requests but could hardly resist the temptation. The outcome in one sense did not matter, the group was recognised as legitimate as they had been approached and whatever happened thereafter did not take that away. So despite seeing the money as potentially "tied" and "restrictive" they applied for, but did not get the grant; and although aware of the great lack of realistic service provision, did take up work in M--.

In contrast some of the groups were self financing to the extent that they were able to give some money away. This was never given to another self help group, although there might be one in the area that badly needed money. The donation was almost always to a health related resource and once to a national disaster fund (Ethiopia Famine Appeal). The group avoided any donation that might be seen as political and despite the fact that it existed in an area greatly affected by the miners strike of 1984-5, there was no question of group money going in that direction. Generally the group donated to resources that their group members might have cause to use or had used in the past.

"Last month we gave £50 to F--- Nursing home for their amenities. We gave £30 to Sister T-- for M-- (Hospital) for their league of Friends. We've given quite a lot to Cancer Relief, every year we give them something." Ethel

So here was an example of a group that not only provided something that the NHS could not provide, but funded itself and added funds into the state provided services.

NATIONAL GROUPS

Self help groups which exist as part of a national organisation may have a different need for legitimisation. In this study only one group (group B) was a local group of a national cancer self help organisation. Communications with the headquarters were few and the group felt that these were generally irrelevant to them. Any legitimisation accorded to the national organisation, based in the south of England, did not filter through to the small Scottish group.

This group did not have any professionals involved closely with it, but perceived other groups as well supported by professionals.

"I suppose we are unique in that we have no professionals in the group. Group A has a Sister, group C has a doctor's wife - we don't have any." Ethel

This was a remarkable statement, not least because of the assumption that self help groups do involve professionals. Ethel implied that this conferred some sort of status that she would have liked for her group. The information is not entirely accurate, group A did have contact with a specialist nurse, but she was not closely involved in the group organisation. The 'doctor's wife' was also a specialist nurse, but it is her personal contact with a general practitioner that is noted, and exemplifies the power of professional contact.

The misconception may have been maintained because the contacts between the groups often took place at meetings where particular experts were likely to be speaking to group A and they invited other groups to attend.

CONTACT BETWEEN GROUPS

The groups were reinforced by their contact with each other. People often saw this as helpful in dealing with their own group difficulties, and sharing their experiences as group members more widely validated the group and them as members. This followed a similar function as the groups themselves in validating the health experiences of the members.

On a local level groups had person to person contact with each other. They might also share resources (eg access to speakers) and invite members from other groups to some of their own meetings.

"It was great to talk to (name) on the phone. She is in a group in (name). They're not so much different from us in lots of ways, it seems we all face similar problems. I've heard that the people who made it to the conference (on self help groups) found the same thing. I suppose you don't feel like you're struggling on your own." Tessa

Any current study of self help groups might take into account the development of a clearing house in England for self help groups (see chapter 8).

PARTICIPATION IN RESEARCH

As the study progressed it became increasingly apparent that there was a two way legitimisation between the group and the research. From the beginning the groups were keen to take part in the study, it did not seem to occur to them that the work could be critical of the group or detrimental to them. They were personally so convinced of the benefits of their group. They viewed the research as another means to represent the group to professionals, and to gain publicity for self help.

Being asked to take part in research was also in itself legitimising for the groups. If someone from the university was interested in them, they must be worthwhile. Indeed the fact that a study of self help groups was seen as appropriate and acceptable to the university and a funding body does reflect the importance of the groups.

SUMMARY.

As a means of maintaining their position next to the formal services, the groups worked hard at legitimisation. They used the management of information and contact with professionals to clarify the nature of the groups and to validate their existence. It appeared that any contact with a professional could help legitimise the group. The groups made use of known local professionals both in their publicity and leaflets to show that they were not in opposition to them. They invited speakers to the group, to hear what they had to say and to strengthen contacts they had in the formal services. They were also keen that professionals displayed group leaflets, and where possible act as referrers into the group again exemplifying the role the group wished to play. The groups were further legitimised, both within and outwith the group, through professionals providing training and back-up for its activities which again highlighted their co-operation.

In addition the groups were legitimised through publicity and funding, particularly where these were in association with professionals. The contact with the research was also construed as contact with a legitimising professional and organisation which construed it as important and interesting. The groups were able to use their contact with each other, and contact with national organisations to legitimise themselves. Some individuals were also aware that they were representatives of the group to their own health care professionals, although this was not without its difficulties.

All these were, of course, part of the normal functioning of the groups and were done for their own purpose as well as having the additional function of legitimising the group. So that the group did want to hear what the speaker has to say, did require publicity, enjoyed contact with each other etc. but these also served to validate the group, especially when they were done in conjunction with professionals.

Clearly these contacts with professionals along with the constraints the group placed on information were ways of making visible that they did not wish to antagonise professionals. Indeed they went out of their way to maintain a reasonable working relationship with professionals in the area. There was seldom another option open to them, and within this context it was difficult for them to act in opposition to, or even critical of the provided services. The groups were confident that what they were providing was unavailable elsewhere, and therefore did not bring them into conflict with professionals. They did not wish to work within the formal services being aware of the compromises that might entail. Nevertheless they still felt themselves dependent on professional support. Indeed, even if they had more clearly recognised their valuable contribution, within the current system it would have been difficult for them to operate outwith it - even if they had wanted to. As individuals they remained dependent upon the same local professionals for their health care. They were in an obviously unequal relationship.

Overall, the means that the groups employed to validate and obtain recognition for their groups worked well. They all had some contact with professionals, and maintained reasonable relations with local professionals. Some groups had a much higher profile than others, which seemed mainly due to their individual efforts and orientation. Interestingly those groups which managed to maintain the most respectful and interactive relations with professionals were those who were initiated by group members, not by health care workers, and who strongly articulated their self help and mutual aid philosophy.

CHAPTER 8 : POLICY AND PRACTICE CONCLUSIONS

The experiences of the women who took part in the study give rise to a number of policy issues related to the delivery of health care services. From the data on the groups there are other, not necessarily unrelated, implications for policy and practice. These range from general concern about health care, to more specific points related to the organisation of groups and the behaviour of individuals.

It may be helpful in this section to follow the general outline of the rest of the work and chart the chronological sequence that most of the women experienced from their first worries about their health, through the treatment phase and then onto deal with the groups themselves. The main emphasis for the purpose of this thesis will be on the practise and policy implications in the latter area. The data were not gathered with a view to sampling an extensive or representative selection of women who experienced diagnosis and treatment for cancer. However, there was little to suggest that the experiences in the group studied here were in any way different from other women with diagnosed cancer. They accord particularly well with those reported in a sample of 1,000 women by Fallowfield and Clark (1991).

POLICY: LESSONS FROM WOMEN'S EXPERIENCE

On the whole, most of the policy implications arising from the experiences of the women in diagnosis and treatment strongly indicated the need for better information about health and health care, as well as placing an emphasis on the importance of good, understandable communication. In addition there seemed to be a need for continuing psychological and social support. These needs are not strongly articulated in some of the groups. One conclusion in this work is that the groups could provide an environment for better communication between members and professionals about health care experiences, and this thesis is partly intended to give a voice to these views.

FIRST SIGNS

The subjective reports of the women when they first had signs of possible cancer emphasised the general lack of information that women had about their own bodies. There were several women who had not noticed the initial indicators of a possible problem eg, lump, or inverted nipple. Once they did they were sometimes unsure of the possible meaning of it. They were not sure if it was something that they should "bother" their GP with.

Indeed when some women took something that did turn out to be serious to the GP and she/he did not recognise it, they were not persistent in their demands for health care. This highlighted the need for general education about health and cancer for women. It is not proposed to enter recent debates on breast self examination and breast screening since the Forrest report of 1986 (HMSO 1986), but the implications of women's anxiety and poor communication had clear implication for policy in any assessment of breast cancer. The data here suggest that women are relatively uninformed about cancer, both before and after

diagnosis and treatment. There may be some excuse for the former, but not the latter. The ways the women chose to educate themselves was within a wider social and health context. This supports the work of Maureen Roberts (see Leather and Roberts 1985) who suggested that education about breast cancer should take place in a wider context.

It was interesting that many of the women in the study had subsequently become very aware of lumps and bumps - and they worried about the implications of them. This was something that they often brought along to the groups, especially to the nurse specialist. Many of them were unsure about approaching their GP. This implied the need for more information to be made available to women in general but in particular to those who have already had cancer diagnosed. These women should also be encouraged to be assertive about their health care needs. In addition more information for general practitioners and other health workers in communicating about breast cancer, and appreciating the fears that women have, seems to be indicated. Indeed any woman presenting with worries about a breast lump, was providing the health care worker with an ideal opportunity to educate and support, and this was not often taken up.

The importance of reasonable communication at this stage was clear from the experiences of one person who had been told they had a "wee something" and been sent along to the "*oncology*" department. The word 'oncology' meant nothing, and it was left to the rather surprised consultant to explain. There were several incidents of this type reported, where people had not understood, or had not been informed. Another example was Lynda who went along for radiotherapy thinking that it was physiotherapy. A mistake that may seem ridiculous to workers in the specialist areas, but the need to occasionally take the point of view of the patient seems very important. Professional staff need to appreciate the importance for effective communication about basic procedures.

One interesting impression that came from the data but could not be addressed within this study, was that part of the difficulty for women was the rapid shift from feeling well to being a patient with a potentially deadly disease. The move through the process of diagnosis and treatment often took only a couple of weeks. Those women who were asymptomatic seemed to find the re-adjustment even more difficult. They had a disease that was undetectable to them, and this appears to affect their perception of their ability to determine their own health status. This psychosocial dimension may be something that research and screening programs might address, particularly as the time when there are a substantial numbers of women still unscreened is limited.

INITIAL DIAGNOSIS

The importance of communication at the assessment and diagnosis stage is clearly important. Early work by Spelman (1965) and Ley and Spelman (1967) showed that people have forgotten almost half the information they received in an out patient session less than two hours previously. The points to be reiterated include the need for simply stated information, to

be repeated when necessary. Emotional reactions also reduce concentration and memory. This was the experience of many of the people in this study, they "could not believe it" or thought that they had heard wrongly.

One novel method had been tried by Hogbin and Fallowfield (1989) who provided tape recordings of the 'bad news'. Although the forty six participants were not formally tested on recall of information, they subjectively reported finding the tape useful. Unfortunately it is not clear from the study what effect taping the interview had on the behaviour of the 'giver' of the news.

Before the diagnosis is reached, there are usually a series of investigations and tests. At this stage many of the women reported that they did not know what was going on, that staff often assumed that what was "normal procedure" to them was also known to the women. Again the emphasis was on the suitability of explanations, and the importance of not assuming that people had an understanding of hospital routine. Some women found the normal "routine" very frightening and bizarre. In addition there were some procedures that seemed hardly necessary at all, eg the photographing of women from the waist to the neck before surgery. Although few women actually complained about this and when a consultant was asked why this happened, he was unable to offer an explanation!

TREATMENT

Even before discussion of treatment options, where there were any, the importance of some explanation of the nature of the disease would seem appropriate. Women often thought that the disease was a localised lump, and had little idea of it as a systemic illness. So when it was suggested to them that they have eg radiotherapy, they sometimes thought that something had gone wrong, and they had not "managed to cut it all out". Of course there will be difficulties with this, but that is no reason why a realistic and straightforward appraisal could not be attempted. Recent research into treatment options (Fallowfield et al 1990) suggests that women do not always opt for the most conservative treatment (lumpectomy). Indeed in the same study it appeared that women generally felt better if they were given the choice of being involved in the decision, whether they took this up or not. There is, of course the need to respect the wishes of someone who does not wish to make a choice, but 'leave it up to the doctor'. The assessment of that in itself may be problematic. However the emphasis remains on communication and information.

Explanations of treatment could be available to everyone who needed or wanted it. Women sometimes worried about the size of the scar, and could be reassured by seeing one (photograph or volunteer). It also appeared that women were keen to know about the actual experience of treatment. This was the type of information that was available in the groups. Women might want to know eg, what radiotherapy felt like. Practical advice seemed to be lacking here too, like the importance of loose clothing, or of organising transport etc. It was often a function of the group, especially when people returned for further treatment, to share the

practical knowledge about treatments. They might also provide psychological and social support at these times.

The range of psychosocial support seemed fairly limited at the time of first treatment. A self help group or volunteer was not available for most people. Those treated in a specialist unit might have access to a specialist nurse. At the time of the study only one of the three 'mastectomy' nurses had received any specialist training at all. A national survey of oncology counsellors and specialist cancer nurses suggests few have any formal training qualifications (Fallowfield and Roberts 1991). Other people were in general wards where there was even less help. However the women who seemed to be the worst off in this respect appeared to be those who had private treatment. These women described themselves as isolated and cut off. They didn't even have the opportunity to talk to other people going through similar experiences.

Although good empirical studies of the effectiveness of counselling are scarce, it is important in providing an adequate service, with trained personnel to allow adequate evaluation.

FOLLOW UP CARE

Once treatment was completed and women were sent home a myriad of issues arose. Often the women felt that they had no practical information, eg how much they could or could not do. If they had had surgery, how far might they use their arm? etc. They worried about recurrence, and the effects on their families and friends. Often women felt that they had left the security of the hospital and they now had to cope on their own. The need for follow up care and continuing information was clear.

One way of maintaining contact was through the regular check ups that the women had at three or six monthly intervals. However many of them felt that these were mainly medical (which they were) and therefore not somewhere that they could discuss their day to day difficulties. Check ups were also heavily laden with anxiety for many women, and they could not wait until they were over and done. They seemed to approach check ups in a similar way to some women approaching screening, ie they saw them as confirming a disease free status that embodied a predictive assurance. Needless to say they often came away feeling that they had not got the information that they had wanted. They themselves would define their worries as "trivial", and say that the doctor did not have time to deal with them. Consultants might have to take the initiative here in enquiring directly about psychological well being. Also the importance of assertiveness and self esteem of the women was underlined. To some extent the groups helped here to encourage women to see their difficulties as legitimate, and help them to put their questions to the professional.

The check-ups may be missed opportunities where women's anxieties and queries might be addressed. This could be done by someone other than the consultant, eg specialist nurse, clinical psychologist in a way that was preventative rather than reactive and crisis based. It was also a forum in which psychological difficulties could be identified and referred on. As

things stood, it was often the groups which provide support and who identified those who were having difficulties beyond the norm. The groups, however, felt that they had little influence in this area, which was defined as 'medical', and some professionals expressed concern about 'unsuitable' people going to groups. Professionals have a role to play here, either in promoting a service that does deal with these issues, or facilitate the groups to work effectively in helping to guide these distressed individuals to the appropriate service.

One area that the groups were concerned about and tried to influence, was the post treatment difficulties with prosthesis. They were keen that women should have information about the range and availability of prosthesis. Some of them had experienced difficulties themselves and it seemed to be defined as an area of influence that was not medical, and therefore within their (psychosocial) sphere of influence. At least one of the groups established links with a local prosthesis supplier, and used their premises as a drop in centre once a week to mutual benefit. Through this all the local groups had access to the nurse who represented that company, who could advise them.

As women returned home they often had to face difficulties relating to dress, and again the groups had much to offer here. Perhaps referral to the group for this reason alone was important, it was the area in which they were the undoubted experts. Indeed it was one of the few areas where they publicly, and confidently acknowledged their expertise.

Professionals might consider informing women about local self help groups at this stage. In order to do so they must familiarise themselves with those groups, and step aside from their professional role in allowing women to make their own choice about going or not. The difficulties in this are addressed later in this chapter.

RELAPSE, DEATH AND DYING

There can be no doubt that women are concerned about recurrence and metastasis. Some authors have suggested that it brings more emotional distress than first diagnosis (Holland 1977), and others (Weisman and Worden 1986) show that 30% of 102 people with cancer thought recurrence less traumatic. Others have commented (Fallowfield and Clark 1991) that reactions are mixed, but for some women it comes as an ending to long periods of uncertainty and anxiety that they had felt since their initial diagnosis. When women do notice another lump or sign, they are sometimes unsure where to go, or what to do. As described above, the check up appointments seldom give them opportunity to deal with these. By contrast the groups provided a forum for checking out how usual or unusual any particular change was, and through this or a brief consultation with the nurse specialist gave the woman confidence to approach their GP or consultant.

The group members provided support for each other when they had to return to treatment, and would accompany each other for radiotherapy, or chemotherapy. But again they did not have good enough links with professionals to get help with problems like anticipatory

vomiting. This highlights the difficulties for groups in working along with and exerting influence on formal services from their relatively powerless position.

At later stages of terminal illness the importance of useful information and sensible communication is obvious. Explanations of seemingly trivial (to the staff) hospital procedure could go a long way to alleviate some of the fears and difficulties experienced by women and their relatives. Non-professionalised language and clear explanations, as well as realistic information should be common policy. The inclusion of the individual, as far as possible, in treatment options would go some way to approaching this difficult time with some dignity and humanity. It may also be important at this point to ensure that relatives, as well as individuals are informed about the range of services available, and the possibility of financial or other practical help where needed.

Unless someone was in a hospice, there seemed to be limited support for those facing death at home. One group in particular, took this as a suitable area for the group in assisting its own members. However, referring people into a group in the terminal stage of illness places an unbearable burden on the groups. They are not set up to deal with that, although part of their remit might be in helping each other face death and dying.

In summary the information made available through these data suggest that the service provision for women with breast cancer has a long way to go. Difficulties with communication and information recur again and again in women's accounts. Many professional workers seem to lack the ability, time or determination to communicate effectively with people who are undergoing diagnosis and treatment for cancer. This might be remedied by an examination of clinical practise, training in communication, and making serious and informed attempts to ensure that people are as informed as is reasonable about the disease, treatments and ward procedure as possible. This might require that all staff regularly review these areas, and also that the role of the specialist nurse receives attention. In addition links with clinical psychologists for help with psychological difficulties (of both patients and staff- including consultants) may be helpful. In this study the groups offered the women help and support, and perhaps professionals need to inform themselves about their local group and liaise with them. Professionals might also consider offering women longer term access and support, which might be mediated through groups. This could include, for some groups, support in the terminal stages of illness.

POLICY: ISSUES ARISING FROM THE GROUPS

Policy issues arising mainly from the group data are structured around several themes. Firstly issues relating to general policy changes in relation to self help groups in Europe are traced. This provides the wider context in which self help might exist - what some might call the 'self help movement'. Then policy implications for the groups themselves are explored. Finally, the relation of professionals and self help groups and possible patterns for involvement are given some consideration.

SELF HELP: THE WIDER CONTEXT

Self help groups in Britain have grown without any great impetus from the Government, and the amount of and value of most self help initiatives remains uncharted. The nature of self help is poorly understood, it is not a unitary or simple organisation. The role of self help as outwith formal provision, is not clearly recognised. Self help groups are seldom able to look after their own members as they would like, much less provide a more general service. Their role as pressure groups, at least for cancer self help groups, is compromised by the problems that brought them to the group in the first place. They do not overlap with formal services, but do attempt to encourage the best use of those services. They attempt to maintain there position 'next to', not in opposition nor coerced into formal service provision. Nevertheless, self help seems to survive and flourish, despite only limited political or practical help from the government.

Humble (1988) gives a brief account of a recent government program in England - The Self Help Alliance. As part of its policy on community care the (then) Department of Heath and Social security provided £1.6 million for 1985-88. The money was distributed to seven national voluntary bodies for allocation to a number of local projects. The scheme was experimental, and accountability was unclear. Support was offered to group leaders with additional information and resource work. Training opportunities with the Tavistock Institute as well as locally were initiated. In addition there was concern to link with other self help groups for sharing of problems, comparing progress and joint training events.

Two other initiatives in the last few years have influenced self help practise and policy. The Self Help Team in Nottingham started from a small group of workers in 1984 and in part, prompted the National Self Help Support Network which is now run from the National Self Help Support Centre and funded by the Department of Health. It employs full time workers and produces a free bulletin four times a year. Its aims are stated as "to encourage support to self-help groups in the field of health and social care, and to focus national attention on the need for such support". It provides information and training for self help members and professionals interested in self help. It also publishes details of research and comment on self help.

As well as these national initiatives there have been moves in Europe relating to self help. The World Health Organisation and the European Community have both offered policies concerning self help. Branckaerts and Richardson (1989) offer a review of this area, and begin by clarifying policy as a formally declared programme and using actual practice as a, sometimes better, indicator of how the policy 'works'. In addition they are aware that the policy may indicate no more than a general 'disposition' in a particular direction. They note that the Committee of Ministers of the Council of Europe in 1980 adopted a recommendation to member states concerning active participation by patients in their treatment, and stimulating health promotion, patient participation and preventive care (Council of Europe 1980). Training for

professionals was to include attention to these areas and recognised patient groups. This had obvious implications for self help.

The second decision making body, the European Parliament, was urged by a resolution from members of the Commission for the Environment, Health Education and Consumer Protection to elaborate a policy on self help. It was argued that self help groups help people take responsibility for their own health care in collaboration with professionals which means better use of resources. The resolution was not passed. Although the European Parliament has shown little interest in self help, this event at least allowed member states to focus on the issue.

The World Health Organisation, particularly after its Declaration of Alma-Ata, and the 'Health for all by the year 2000' (WHO 1978), articulated a concern with social aspects of health care. In the late 1970's Dr David Robinson was appointed consultant to keep a watching brief on self help developments. At a workshop in 1981 recommendations were made for the establishment of an information centre in each region to exchange information on self help, promote research on self help and the inclusion of self help in WHO work. Branckaerts and Richardson (1989) argue that this was in some ways counter productive:- as all divisions of WHO had to take responsibility, it actually meant that no one division did so with any urgency.

Europe was appointed as a pilot region and the Regional Office for Europe, particularly the Unit for Health Education took an active stance on self help. Stephen Hatch (1980) provided a report for the regional Office for Europe, and recommended the establishment of a European clearing house. This became known as the Information Centre on Research into Self Help and Health. The WHO subsequently published 'Self Help and Health in Europe' in 1983. In 1984 the Information Centre moved to Leuven in Belgium and became known as the International Information Centre on Self Help and Health, and takes an active stance in promoting self help in the WHO.

Overall there has been a series of different attempts to articulate and act on policy in Europe on self help. The main effects seem to have been an indirect legitimization of self help - at least it is somewhere on the political health agenda. The existence of an information centre had implied approval for that model and the English National Self Help Support Centre can be seen to follow on those lines. Branckaerts and Richardson (1989) conclude

"With regard to self help..this is not a live political issue in many countries. There is no broad political base to press for specific policies, although there may be interest in greater facilitation of self care. Self help remains - and probably will remain - a fringe activity, concerning a small proportion of any given population. On the other hand, it tends to be viewed as a generally welcome phenomenon, fitting easily within most political ideologies. Those who seek to extend mutuality and fraternity see it as one expression of these goals; those who seek, in contrast, to extend self reliance and independence also consider it to be an expression of these aims. Thus while there may be little broad political pressure *for* self help, there is unlikely to be strong pressure *against* it." (emphasis in original)

So self help can fulfil a variety of political objectives, and could be co-opted by the political left or right. The nature of self help seems to determine that it exists outwith the major

political structures, and perhaps that is an advantage. Self help has existed, and continues to exist in a state of tension with the formal services. There could be a danger if it was amalgamated within those services and this will be examined later in this chapter. Up until now self help has been started and maintained by its participants because that is what they wanted and felt they needed. Major policy statements have not been required up until now. Perhaps the current environment of sceptical tolerance of self help is a reasonable milieu for it. Indeed it may be the only environment as "self help is of marginal concern to most service providers" (Unell 1988). None of the groups in this study knew of the European developments never mind felt that they had been influenced by them. They, at that time, also had no contact with the National Self Help Support Centre. For groups in Scotland, that was perhaps understandable as Government initiatives had only been for England. The Manchester groups, however, were geographically quite close to both Nottingham and Leicester.

In recent years in Britain the National Health Service review has prompted changes in health care that may have a bearing on self help. The strategy document of 1989 (Smith and Jacobson 1989) concentrated on prevention, without mentioning self help at all. On the one hand the White papers 'Working for Patients' (HMSO 1989) and 'Caring for People' (HMSO 1990) emphasise the importance of caring in the community and participation in health care, on the other demand an economically-led approach that may be inconsistent with the aims of self help. They want a commitment to 'value for money' studies. It could be argued that self help provides a community based resource that enables people to make optimum and appropriate use of the formal services. They demand little in cash terms from health and social services. However, their role as both service providers and customers is not easily accommodated. There are likely to remain some tensions here. Thus small organisations may be tempted to take money from the local authority in order to provide a service, and then find themselves locked into a service-providing contract. They continually have to balance the needs of the individual with the needs of the organisation. Gutch (1990) comments on some of these difficulties. As the assistant Director of the National Council for voluntary Organisations, he is concerned with "the contract culture". He recommends discussion with local development agencies and local authorities, but warns that "...it is important that the voluntary sector is not left to do more and more with fewer and fewer resources". He suggests that an advocacy role may be a better way of working with groups representing service needs and monitoring quality of provision.

The relationships groups have with professionals may come under review. Although there may be an apparent strong commitment to consultation and listening to the 'consumer' this often falls short in practice. Pitkeithley (1991) looks at some of these and comments,

"Both consumers and professionals have got to do quite a lot of attitude changing before consultation is going to be a reality....it becomes apparent that although there is a great deal of commitment, the service providers have the greatest difficulty in hearing what we are saying. Because they have their own agenda, it becomes harder and harder to make them hear what it is the consumers are saying.

..The first is the imbalance of power which exists between them. It is very difficult for service providers to realise how powerless consumers feel in the negotiating process....The second thing is language.”

There is also a dilemma for self help groups in their links with formal services. Not only do they wish to take part in consultations, but they need to remain separate from those services in order to continue providing real self help. There is also the additional fear that self help may be used to fill the gaps in service provision. An editorial in the *Journal of Social Policy* (1976) acknowledged that self help could be ‘politically risky’ because ‘it hides inadequate investment in social services, detracts from systemic inequalities and short comings, and denies widespread exploitation and oppression’. If that was the case in the mid 70’s, how much more so now. Mitchell (1884) also argued that self help was ‘seen explicitly as a way of saving money’ and to encourage self help was politically ‘incorrect and dangerous’.

It is essential to clarify the role of self help, as a unique type of mutual help that is not, and cannot be available in the formal services. Once self help moves outwith that function, then it may become politically risky. The ambiguity of interpretation of the aims of self help are again highlighted. The National Self Help Support centre has attempted to address this issue and made it clear that self help is not a cheap option. They define self help as complementary to service provision, with a role in empowering their members to make best use of those services provided. That is firmly adopting a stance along side formal services without necessarily losing identity within them or overtly challenging or opposing them.

In terms of attracting support and funding, the groups have to toe a strange political line, that ensures that they are offering something that is of value, and is acceptable to professionals, but not to be seen to be taking over or compromising existing services. Currently they also have to be of sufficient value to warrant any professional time, as health professionals are increasingly called to account for their time, and place a monetary value on their work.

The rest of this chapter will provide some simple policy and practise recommendations to self help health groups, based on the data available in this work. Then the complexities of relations with formal services will be commented on, again using the information from this study. There is no doubt that interesting work could be done in the nineties in charting the changes in health self help groups in relation to the changes on-going in the National Health Service.

POLICY: ISSUES FOR SELF HELP GROUPS

Since the National Self Help and Support Centre was set up, it has provided many self help groups with help and information about self help. Groups have to consider a variety of factors in starting up and maintaining themselves. The Centre can and does provide some useful guide-lines and several ‘starter packs’. In addition they recommend Judy Wilson’s “*Self*

help Groups: Getting started, keeping going." (Wilson 1986). These make general recommendations for groups, some of which also appear here. They have also been involved in reporting in their bulletin 'Mutual Aid and Self Help' (MASH) new groups, research and details of workshops and conferences for self help members and professionals. They also provide trained workers to come out and advise groups when they are getting stuck. None of this was available at the time of this study, so it is impossible to comment on this in practise. However it is a valuable resource for self help groups, and any group getting started would be wise to make some contact and use the expertise available.

The issues which arose from the present study are issues that seem to affect many self help groups, but have particular relevance to health and cancer self help groups. The first policy and practise decision that groups have to face, is who is the group for, and what are they going to do? From the preceding section, the importance of articulating some directional policy should be clear. The function and aims of any group are open to political misinterpretation. Each group studied was different, and this makes it difficult to articulate specific policies. Most faced similar hurdles, and examples of good practice observed form the basis of general policy direction.

Most of the groups in this study were started by members, and those details are available elsewhere. Two of the groups grew out of a fading group, two were initiated by enthusiastic individuals with some help from professionals. Two were initiated by professionals in a self help format. The groups were influenced by the initiators. These data emphasise the importance of the initial meeting, as a large number of those involved in the group at that time continued to play important roles years later. The organisation adapted to them, and they to its changes, which of course, they helped to determine. When tasks were shared at that meeting, they continued to be shared. If an authoritarian style of leadership emerged - this also tended to continue. Where professionals immediately devolved responsibility, this continued to happen, and where they retained control, they later found it nearly impossible to relinquish. The first meeting, then, should be given some consideration, and people's enthusiasm maximised and harnessed. As well as the excited sharing that goes on at these first meetings, it is essential that the group formulates some policy about organising the next meeting, and discusses possible types of format and starts to formulate the aim of the group. Although the groups did change considerably over time, they were also markedly consistent in maintaining their organisational structure. One group had articulated to the researcher their plans for the future, and several years later had moved considerably in that direction. A casual meeting with a group member some years later suggested that they had forgotten that statement of their aims, which they had followed nonetheless. This research suggests that the groups adopt a policy of articulating and if possible recording their aims and

enthusiasm in the early meeting. These are then overt, and therefore open to discussion and change.

Groups could also be made aware that there is a crucial time when people are most likely to seek out self help, and ensure that information about the group is available to them at the time. Many of those interviewed and attending group meetings joined the group four to six months after diagnosis and treatment for cancer. They were at home, away from hospital, feeling isolated, and uninformed, but having to face a future which included having had cancer. An ideal policy would be to make the group leaflet available at the three month check up, or have a professional inform women of the self help group around that time.

Information about groups is crucial. Their publicity determined who got to know what about them. It is essential to target publicity at appropriate groups, ie potential members and possible referrers. From this study it appeared that people came into the groups by reading group leaflets, seeing or hearing a program or article on self help, or through personal contact with a member. Some people were referred by a professional. The groups might usefully review all these means of referral into the group at regular intervals to ensure their optimum use. They could also explore other means of publicising their group eg church magazine, posters, open days etc. Local professionals may be of help here, and the National Self Help Support Centre offers training in publicity. In addition they may need to consider the drawbacks as well as the benefits of possible systematic referral. They are, and by their nature are likely to remain, a limited resource.

All the groups in this study recognised that new members had specific needs, and changed their practice during the time of the study to facilitate the entry of new members. Making some personal contact with a group member seemed to help people first attend a meeting. Also appointing someone to specifically look after new people at meetings was helpful. Having a number of 'older' members to introduce new members and befriend them for a couple of meetings also worked well. In some groups specific meetings were organised to introduce new members to the group, and this was also successful. In essence, groups have to recognise that new members have particular needs that can be met by a variety of group policies and practice, but the issue does need to be addressed.

Groups also need to decide if they are going to keep records of members for publicity, or newsletters, and articulate their policy on that. Again this could be reviewed and amended, but it seemed to help if groups were clear about record keeping. Most of the groups in this study decided it would be maintained on a voluntary basis, ie members volunteered their name etc. and could request the information to be removed or updated. This seemed to work reasonably well, although the records were seldom completely accurate or up to date. Some devised a yearly review, where those on the list were requested to make some response in order

to keep in contact. This saved people from having to make an obvious withdrawal from the group, and made sure addresses etc were reasonably accurate.

The location of the group meeting seemed to be fairly important. In this study some groups met in members homes, others in hired premises (community offices, church rooms), and only one in Social Services property. All had made a decision to keep the group away from health related properties. All the groups expressed reservations about meeting in hospitals. Any new groups or facilitators should note this.

Some of the groups in this study successfully reviewed their membership to include a wider range of people (people with cancer to people with pain). Others remained distinctly defined as cancer, or breast disease groups. Some groups welcomed relatives and friends, others found it impossible to accommodate partners (male). On the whole it seemed that there was no distinct advantage to any particular format, but the group had to be clear who was able to be involved, and present that as a ground-rule. It could be changed, but at least it needed to be articulated. What was clear, was that the most successful groups persistently canvassed members for new information about the group and new ideas. In this way the group moved and changed to meet a variety of needs. In addition it was helpful for groups to look outwards.

All the groups in this study organised a variety of group meetings at different times and frequencies. This seemed to work well at addressing the various needs of group members. Some attended some meetings and not others. This made possible the widest participation. Groups might therefore adopt this as a policy, and not try and do everything in one group meeting. Similarly the numbers of people at meetings needs to be thought about, and was something that concerned group participants in this study. Most groups felt that support and mutual aid could best be achieved in small numbers and when the group grew larger split into several small groups at least for part of the meeting.

So groups had meetings that were for support mainly, meetings for information and times when members or outside professionals gave a talk and things opened for discussion. Other meetings were to deal with administrative and organisational matters, and others again for fund raising or 'dropping in'. The format of each of these meeting was slightly different, although all members would be encouraged to participate. In addition one group also had spiritual development meetings, as well as art therapy and relaxation. All these meeting worked well, and each group had grown in response to members and the groups' needs. Thus some groups dealt with administrative matters in addition to a purely social meeting. This took the pressure and rigidity off the organisational component, and encouraged participation from those who would have avoided a 'committee' meeting.

For a variety of reasons, most of the groups had a structure within the membership. Thus a Secretary, Chairperson and Treasurer evolved or were elected. One group did this in

accordance with the requirements of their national parent body, another reluctantly to formalise the group for registered charity status. There is no doubt that the self help groups studied here needed some of this structure, for external validation, and in some cases to facilitate the running of the group. On the whole they attempted to de-formalise these positions, and encouraged any of the members to take part. In one group that had been started by professional workers the members were far more reluctant to take on these roles. The 'professionalisation' of the running of the group made it difficult for the women to assume responsibility.

The range of participation in the group also needs to be addressed, so that people know what is expected of them in the group context. Although participation seemed to help people to help themselves and each other, it was also sometimes seen as a cost. Some groups were trying to get members to participate a bit more. Those groups who stimulated the greatest range of participation were those who encouraged people to help on the smallest of tasks from as early as possible. These groups also devised numerous 'working groups' to deal with each aspect of the administration. Thus four or five people looked at funding, a number got together to contact speakers, others took responsibility for booking the meeting room etc.

There is no doubt that 'special people' become identified in groups. These were often, but not necessarily, initiators of the group who had played a major role in its development. These people seemed to be fairly central to the group, often playing an organisational or major social facilitation role. It is important to ensure that these people can move on and if need be, away from the group. This was most successfully achieved in one group where the initiator of the group continually devolved responsibility and encouraged participation. Although the group tried to maintain him in a prominent role he gradually and persistently faded his input. To some extent this was facilitated by his open discussion of his needs and development. This policy seemed to work well and could be recommended. Not only had people gradually taken on more and more of the group running, but they kept in touch with Mat as a person. He also resisted attempts to label him as the group leader, and from the beginning of the group ensured that a number of people were involved in running the group.

In other groups the issue of leadership was not so clearly addressed. In the professionally led group there were particular difficulties, as already mentioned. In other groups there was a tendency for people to get 'stuck' in offices or roles. This could be easier if group members ensured that the running of the group was open and available to everyone, and participation at all levels was encouraged. In one group the leadership provided many difficulties for the group. The group initiator could not let go of the organisation of the group, and scared other people when they attempted to be more involved. Quiet intervention from outwith the group did not markedly change this but helped alleviate the situation. Unfortunately this type of group is unlikely to survive the group leader. Groups might make it a policy to

maintain open discussion and to de-mystify the group management, allocating small tasks to a number of people. There will, of course, always be some people who do not wish to take an overtly active part in the group organisation. Most people, however, participate and contribute at some level, and groups might use this approach to help people understand mutual aid and self help. It may also help to prevent the emergence of an 'elite' within the group.

Group members who had been around for a time (often years) had a particular role to play in continuity in the group. It is important that they are given opportunity to explore different options in participating, and eventually leaving the group. The philosophy behind self help would suggest that more experienced members pass on their learning to newer members. Richardson and Goodman (1983) called this 'serial reciprocity'. Certainly people who stayed in the group for a long period of time managed to take on a variety of tasks and roles at different times. Other, who were members of the group, remained on the list for the newsletter for years, and seldom, if ever, turned up at a meeting.

New members pose other difficulties. As discussed in the section on first attending the group, all the groups in this study modified their 'new member' policy in the light of feedback, and their own experience. Most moved towards encouraging new members to make contact with a group member before attending a meeting, and encouraged initial attendance at a group meeting that had a large social and supportive element. This seemed to be good policy, and worked reasonably well in practise. So the misconceptions that potential members had, as exemplified in this study, were cleared up to some extent. There were, by the nature of self help, people who made their own way into the group at random times. A good policy had emerged for a small number of members to act as 'befrienders' to new members. Two of the groups ensured that everyone was met at the door, and new people were identified in this way. At one meeting new members were asked, during the meeting, to stand up and identify themselves- a difficult task in a large meeting (of about 27 people). This was not good policy and was quickly dropped. One group had a particular meeting set aside for new members, to ensure they were attended to.

Groups eventually came to consider funding and expansion or change. The best practise that was observed was the evolution of a 'funds group' within the larger group. A small number of members took on the task of promoting funds, and did very well too. The participants remained in the subgroup for only two years, or less at their request. This group approached local firms, the council, the health board, other voluntary agencies, other cancer agencies, the general practitioner committee etc, at each step broadening their ground. This worked well, and is something that other groups might consider. Most of the groups agreed that fund raising was a means to an end, not an end in itself. It was seen as a group activity that

helped the participants; they were doing something together. In addition they were legitimising the group.

Some of the groups produced leaflets. Where these touched on medical issues they had them validated by a health professional. This was a good policy, as it made it acceptable to professionals, and legitimised the group. Some of the groups produced a yearly program, or a regular leaflet about it's proposed program or reporting on its activities. These were distributed to a wide range of people, both participants and professionals, and provided a useful update of, and contact with the group. They also helped legitimise the group, as the program inevitably listed several professionals speakers, as well as the honorary patron. This policy worked well, and took minimal effort for maximum gain. At the time of writing the researcher still receives literature from two of the groups in the study, despite several years elapsing, and major changes in those groups. Distribution is controlled by the 'only by response' review mentioned above.

Some of the groups began to develop a small library . This seemed helpful for members, and gave access to literature that may have been difficult to find or too expensive to buy. Often the groups were advised by professionals as well as following their own experience.

As each group is different and responds to local needs, it is difficult to determine exact policy. An attempt has been made to outline those policies and practices that worked best for the groups studied here. At the same time, it is suggested that each group comes to some understanding of their own aims and articulates these at some level. This avoids political misinterpretation. The groups who worked well were consistently informed by the principles of self advocacy and individual choice. They moved and changed to accommodate differing perspectives within a group, and were concerned to maintain their group. The organisational decisions were discussed and open to all members, and thus demystified. Where several groups existed in a small geographical area, it seemed to help if they maintained some contact with each other and shared information and resources and training opportunities. This is an important element in enabling self help, and embodies the principles of mutual aid at an organisational level. The relations that groups develop with professionals is crucial. The next section will deal with this in some detail.

POLICY: RELATIONS BETWEEN SELF HELP AND PROFESSIONALS

As suggested in the literature review, there seems to have been an assumption made that groups are able to determine their relations with professionals. This study suggests that they are not usually that powerful. These groups, which deal with health and illness, exist in a world full of professionals. At most they can influence their relations with them, but they seldom have the option of existing outwith that world. The groups studied here were interested

in sustaining good links with local professionals, and saw this as mutually beneficial, but not without costs. None of the groups attempted to work in opposition to formal services. Professionals, too had an interest in self help groups, but maintained some reservations about accountability and effectiveness. Issues of power and control, communication and expertise came up repeatedly when examining the interactions of self help groups and professionals. Many professionals had not considered that additional professional input might have to be moderated or that it might be anything other than a benefit for the groups and what they did. This section looks at possible ways that the relationship between groups and professionals might be negotiated.

The groups and professionals at the time of the fieldwork had not had to deal with the changes brought about by the National Health Service reforms proposed in the late eighties, but where these affect possible practice and policy they will be referred to. In relation to this, it was notable that most of the professionals' involvement with the groups was not seen as a part of their job. Most contact was quite separate, and often took place in the evening. With clinical audit, and other measures of accountability for time, this may have to be reviewed. For those professionals who had managed to incorporate their contact with groups into their work, they may be called to justify that.

On the whole professionals and group members agreed on the benefits of involvement in a self help group. These included support through sharing experiences, access to information, an opportunity to help others as well as oneself and increased awareness of professional systems. In addition some professionals felt that groups could act to pressure for change in services, and were pleased to have a new forum for interaction. The drawbacks envisaged by professionals were more consistent with members expectations of groups than their real experience of them. These included concern about the age and health of members, possible confusion over treatment, and witnessing deterioration in others. Experience in the groups allowed people to deal with these possible drawbacks, and it might be that professionals could sharpen their views of groups by closer contact.

Many professionals, although they had some contact with the groups, were also remarkably uninformed about them. They seldom knew when or where they met, and often only had a vague notion of what they did. Professionals might be encouraged to seek out this information, and distribute it amongst colleagues. Maybe this is the first task for self help groups in helping their relations develop; they need to inform professionals about the group. In particular they perhaps need to address the particular misconceptions about self help that some professionals held, and demonstrate their benefits to both members and professionals. Thus professionals need to know about the experiential sharing that helps people, and work to separate that from comparison of medical management. Professionals need information to see

the groups as a social not a medical phenomenon, and recognise that any threat to the medical and professional establishment, if it exists at all, resides in the different philosophy of the self help approach, and not with the group and members per se. The groups in this study did not intend to oppose professionals. Professionals and groups need to work together to maximise the role of the groups in education about health, and to use the groups as an empowering health care opportunity. In addition professionals could come to see that they have much to gain from involvement with self help, not only in access to a forum where they try out a different approach to health care, but also where they can learn about the personal experiences of illness that might inform their clinical practice. Self help groups are not there to threaten professionals, but by their existence may challenge professional assumptions about responsibility and professional expertise.

Groups may have a hard task in convincing professionals, and for many it would be easier, and legitimising, if professionals took the first step. In this study groups seemed to convince other professionals more easily when they involved a number of professionals in the group, often initially as speakers. Involving professionals in this way allowed them to operate, to some extent, within their professional mode, and experience in the group often allowed them to see what the group was about. Groups often successfully maintained links with one or two professionals who then legitimised the group. For example, the Scottish groups found a (not uncritical) ally in the Director of the Breast Screening Clinic. She acted as an advocate for the groups and facilitated training etc.

None of the groups in this study were set up as a challenge to or in direct criticism of medical treatment. They acknowledged the technical expertise of medical treatment, but recognised there was little psychosocial support for them. It was a response to lack of help, support and information about their everyday life concerns. The groups were not set up as incompatible with treatment, and the initiators and members went some way to emphasise this. It was not in the groups' best interest to work in opposition to local professionals.

Given all the difficulties in setting up a group it is a wonder that any get set up at all, or thereafter continue to function. Initiators tackled difficulties in contacting people, in gaining publicity, and in finding a location for their group. Clearly there is a role for professionals to respond here. They have information about resource, funding etc that may not be immediately available to a group. In addition they may have access to potential members. Practical help was often difficult to find, and was something that most professionals had not considered offering groups. It is also at this stage, even before the first meeting is arranged, that a professional might have expertise to offer about the functioning and processes of groups. If there is no member with experience in group work, a professional could help here.

Nurse counsellors seemed to have a particular role here too. Often their orientation was similar to those of the group - a concern about the psychosocial aspects of breast cancer. In both areas the local nurse counsellor was involved with the groups. She was able to act as a mediator for the group, and found the group a good way to offer people additional health care.

Although there may be a role for professionals in self help a group that is run by a professional is not in reality, a self help group. It may be a professionally run group which uses self help principles. The members may be encouraged to interact in the mutual aid principle, but the responsibility remains with the professionals. This is a difficulty where groups self help groups are organised to exist 'within' the formal services. In this study group E, was set up by social workers. The resources that they could offer (a place to meet, help with printing leaflets, a direct referral system etc) were helpful and available. These were the things that other groups struggled for. However that group never quite managed to move away from the professional-dependent mode. The women were in a sense socialised into dependence, no matter how much the social workers tried to make it otherwise.

It is clear that in attempting groups 'within' the formal services is not easy, and may indeed not be possible without compromising some of the bases of self help. Although the group was a health related group, it is interesting that it was set up within the social and not the medical services. The group used its contacts with the medical serviced to provide legitimation. So the question arises, what services are groups likely to be set up 'within'? Significantly, in that group the nurse counsellor took a different role from the social workers, and her position in the group was much more comfortable. She took on the function of an additional layer in the primary care system. She did not assume an organisational role.

There is no doubt that the group did much to help women, but the interactions and responsibilities in the group were very different from that in other groups that had been more determined by the members. A discernible difference in the balance of power and confidence was apparent. Whereas group F, in the same city, had a wide remit, a variety of meetings, a phone line, as well as the back up of a variety of different professionals (including training from them), group E developed few of these. Trying to get the women to take an active part in the decisions about possible speakers was portrayed as a struggle, by both the women and the social workers. It might be argued that this is a function of the population of the two groups, group F being a general group that included relatives, while group E was strictly for women who had had breast cancer. The information available here seems to suggest that the principles on which a group is set up are pervasive in their influence, and it is the self help focus in the first instance that largely determines who does what. Comparison with other groups, eg group A, which was also a specialist group, indicates that similar difficulties arose in that group too,

but not to such a great extent. The women in group A did organise their own activities, invited speakers, organised a drop in centre etc

It could be argued that while group E was set up as a self help group 'within' the formal (social) services, group F was defined as operating 'next to' a variety of services. They maintained this model by their association and contact with social, medical, and psychiatric services. They were therefore able to maintain links with a variety of professionals from several disciplines, and not be co-opted or wholly identified with any. This was a much more flexible arrangement which was more likely to meet the changing and divergent needs of the members.

Similarly, the type of professional interaction may be crucial. Group C, which had lots of professional input from a specialist nurse, did not experience the difficulties in group E to the same degree. The women were willingly much more involved. This group was a rural group, but the style of input was very different. The nurse, from the start encouraged women to take responsibility for its running and organisation. Thus this group could be seen as emerging from 'within' formal health services, but being largely maintained 'next to' that.

The overall impression remained, that the group with the biggest conventional professional input was the one that experienced the most difficulties in motivating members to participate. Too much professionally led involvement undermines the principle of mutual aid on which self help is grounded. It also emphasises the difference between self help and professional groups, the one encourages autonomy, the other, albeit unwillingly, dependence. This highlights the major difficulty in any attempt to merge self help with formal services. They have to remain distinct in order to operate as a self help group.

Where professionals are involved in helping groups to start up (or keep going) it is essential that both parties recognise these influences. Professionals do find it difficult to relinquish feelings of responsibility, and therefore should not take on too much in the group, otherwise they will feel responsible for it. Perhaps they need to constrain themselves to practical help and respond to requests for advice etc. in a consultancy role. Members, on the other hand, need to protect themselves where they can, from becoming dependent on professionals, and to ensure from the beginning that the group remains self help in its organisation. Articulating the group aims in this area early on seemed to help everyone to revise their positions. The difficulty for professionals working within the constraints of their professional role are unlikely to be able to relinquish that professional responsibility, and it is unfair to ask them to do so. The possibility of a self help group operating wholly 'within' the formal services seems very unlikely. The consultancy role, where the consultee presents their case to the consultant for advice, but it remains the consultee's responsibility to take or not act on that advice might initially provide a working model. Thus the responsibility remains well defined for each.

Whether professionals should refer people into a group should probably remain a local matter between individual groups and professionals. However professionals should be informed about groups so they could in turn inform potential members of their existence. In the spirit of self help they can then make their own way into the group, or not. There seem to be dangers where professionals refer into groups without having a clear idea of the extent and limits of the group (eg referring people in the last few days of terminal illness into a group that helps its own long term members approach death). The changing nature of the groups would require regular contact and update. It also seems possible that not only might the groups be overwhelmed by systematic referral, but that in itself may change the self determining, participatory nature of self help.

One particular task the groups have to bear in mind is convincing professionals that they do not overstep and interfere in medical management. Most of the groups did this through the legitimization techniques mentioned in chapter 7. Professionals often came to an appreciation of the groups' activities through contact with the group, and hearing about it through their patients and other professionals. Groups should be aware of this and realise that talking to their doctor about the group is important.

Many professionals were able to appreciate the group was social rather than medical in orientation. The groups' programs makes this clear. These professionals were also aware of the social impact of the disease, and there were psychological consequences for women with diagnosed cancer. Many were aware of lay misconceptions about cancer and were able to see the groups as an opportunity for health education. The groups were always keen to learn about the disease and treatment, and invited professional speakers. Professionals might be made more aware of the role the groups play here, as they often disseminated information. The information leaflets produced by the groups were also an opportunity for collaboration in education. Neither should feel too fearful of accessing the expertise of the other.

The groups were concerned about the impact of cancer and the treatment of women. People often came to the group for information and support. Their experiences had taught them that the medical system did not deal with psychosocial issues. Unfortunately the groups did not often take up these issues with experts. They would often ask for information, but seldom for explanation. Although it would have been relatively easy to translate a personal issue into a general question, this, at least during the participant observation, was not apparent.

Thus the groups did not always pick up on areas that concerned them, and professionals did not always have access to the personal accounts from individuals. It may be that too much caution was being exercised here and there might be value in providing an opportunity for relating personal experiences. Illness, after all, is a very personal experience. From the accounts that people gave there was much valuable information that professionals

might benefit from. Some of this is discussed earlier in this chapter, but in essence indicates the continuing difficulties in communication during and about the process of illness and treatment. The accounts of women also highlights the lack of understandable information available.

These are issues that concern the groups and they contribute towards rectifying them. The group provides a forum whose value has not really been fully appreciated in providing professionals access to this type of personal information that is seldom available elsewhere.

Some of the groups arranged regular meetings where members could talk about their own experiences. Professionals were not excluded, but not particularly invited, it was something that the groups dealt with on their own. This may be an area where professionals have much to learn and the groups much to give. However, the constraints that exist are there for a reason and should be respected. The groups should retain the power to decide here, and maybe it is, as of yet, an area where they are unable to incorporate professionals. Nevertheless, it is an area they should be encouraged to explore, not only for the support of other group members, but also for the elucidation of health professionals, and the improvement of the service.

On the issue of professional involvement, group members were, on the whole, cautious. They wanted to retain control over their group, and were concerned that professionals, while helpful at times, might take over the group. Despite this they all maintained good relations with a variety of professionals, and maximised their contact in legitimising the group. Some groups spent time in co-opting a range of professionals to 'back up' the group and involved them in training programs. These groups had accepted the limits and skills of the group and of the professionals. Both professionals and the group had chosen to be involved and worked out a format that made it possible. Other groups would have like more involvement with professionals, but were not sure how to go about it.

Some professionals interviewed in this study offered a view for the future of involvement with self help that suggested they had not considered giving groups a choice in the contact. They assumed that a better format for groups would be inclusion into the services they represented, and more involvement with a professional. The potential for the professional to dominate the group had not been considered. The elements that have been seen to promote the groups, ie existing outwith the hospital, run by members, egalitarian membership etc had not been recognised or considered. It is therefore important that professionals and groups who are considering closer collaboration recognise these issues. The suggestions are that professionals, on the whole, find it hard to relinquish their professionalism and put aside their professional role and responsibility. This should not be surprising. It does represent a considerable departure from a professional model, no matter how 'self help' it may appear. This had been

shown in other studies (Mantell 1983, Robertson and Reed-Purvis 1991). In this study it was particularly apparent in one group which had been initiated by professional workers. Its members resisted all attempts to make it 'more self help'. This suggests that it is hard for professionals to set up groups and than 'fade'. The main impetus must come from the members themselves.

To summarise the preceding section, it is clear that self help groups have much to offer. Indeed their unique contribution in the field of health care and promotion has only recently been recognised, and is in danger of being overlooked or misused within the context of a financially determined health service. This study has attempted to clarify what cancer self help groups do, and also what they do not do. They have their limitations, not only with regard to the individuals in them and to whom they might offer help, but they are also constrained as organisations.

Professionals might play various roles in facilitating or promoting self help groups. However all have to be aware of the balance of power and autonomy that helps or hinders this relationship. Fairly minimal input from professionals has exponential benefits for the groups.

What the groups wanted from professionals was help with recruiting and educating members, with gaining funding and sometimes practical assistance. These were areas that professionals had seldom considered. The groups also needed access to help and support, and some advice. The best model for this was offered by group F who had a wide range of professionals as a back up for the group. This had been established over time, by persistently including professionals in the group, and taking up offers of help.

In that group, they had also developed a training program for telephone volunteers. The groups sought help not only with information, but also about techniques. This is an important distinction that groups and professionals need to make. In addition the groups may require training on group dynamics, and help with understanding the processes in the group. This is best done on a consultancy basis, by a professional with the appropriate skills who remains essentially outside the group.

As previously indicated the groups and professionals need to address the fears that each have to allow good interaction and support. Essentially both need to review their assumptions about power and expertise. It is essential to differentiate between technical and experiential expertise. Essentially, if professionals are going to be involved productively in self help groups, then they must be prepared to shed their assumed power. They are people with special skills, but no more and no less than anyone else who might be involved in the group. In fact, they may lack the specific experiences that drew people into the group. This requires a different mode of working from usual, and also requires that the professional remains quite clear sighted about the group and its activities. It is not a professionally run group and does not

take professional responsibility. This is something that requires a shift away from conventional training, and if professionals are likely to be able to facilitate these sort of groups then part of their training must emphasise that.

Groups, in turn, have to decide where and how they adjust their mode of operation to accommodate acceptance by professionals. They must consider legitimisation and its cost to them, and recognise their own and professional expertise.

The next chapter will present the main conclusions of the study.

CHAPTER 9 : CONCLUSIONS

This chapter will cover the main points raised in the introduction to this work in the light of the information now available. A brief summary of the main points about the groups will be followed by consideration of the main points raised in the introduction. Particular attention will be paid to the question of group definitions and to the issues raised about relationships between self help groups and professionals. Briefly the main conclusions suggest that these self help groups are complex and interesting organisations which do not easily fit into any typology so far available. The data confirm the inclusion of, or at least consideration of, groups' interactions with professionals as part of any understanding of self help. In addition the notion of self help groups as necessarily challenging to the status quo needs to be revised, as any challenge offered by these groups was inadvertent. Indeed it has become clear that these groups are generally keen to maintain good relations with professionals, in order to legitimise themselves, and are unwilling to act as pressure groups. However, some professionals do not have a realistic idea of the groups or their work. Many professionals were keen to co-opt the groups and bring them within their own services with no understanding of how that might change the nature of the help offered and without having considered what type of relationship might be possible with such groups. Where professionals were involved in the groups in an organisational way particular difficulties arose that highlighted the problems with this liaison. In particular the tendency for participants to relinquish autonomy and the professionals to define the activities and roles. The difficulties for both professionals and for groups in developing a good working relationship are highlighted.

THE GROUPS

The information now available about the groups will be summarised, with particular attention to their general functioning and the experiences of the group members.

The people who eventually went along to a self help group had a variety of differing health experiences. Most had noticed something unusual themselves, and sought help through their GP. A few had attended a well women clinic for breast screening. To some extent the sample of women in this study will now (at the time of presentation of the thesis) be an unusual group with the advent of the screening program. For many the rapid change from being 'healthy' in their own eyes to being diagnosed as having a life threatening illness was quite shocking. Although most women appreciated the speed with which treatment went ahead they found their own adjustment to the new health status very hard. It remains to be seen whether this adaptation is more difficult for asymptomatic women who had cancers detected through screening. (Research in this area is underway, although still at the pilot stage in the West of Scotland).

Many of the women in this study had few concerns about the actual procedure that they went through. Most of them accepted their diagnosis and treatment without question. Many

did, however, comment on the lack of explanation given to them about the various procedures that they went through, and were concerned by a general lack of information and a feeling that they 'just had to get on with it'. There is little doubt that health professionals have moved to try and deal with some of these issues as is evidenced in the volume of work quoted in Fallowfield and Clark (1991).

Women went through quite a change in self image, that related not only to their body image, but also to their perceptions of themselves. This was particularly evident when they returned home, back to 'real life' and some semblance of normality. They now, along with partners, family and friends, had to live with cancer. It was generally at this point, particularly a few months after returning home that they sought out other help. Even where there was a health professional involved in the self help group and the woman knew about the group before this time, it was unusually for people to attend a group meeting or to contact a group much earlier.

Each of the groups in this study had a different history. None were more than three years old at the time of the study. Some had been started with a lot of help from professionals, or totally arranged by professional workers, while others set up on their own, sometimes emerging out of another, similar group. Most people went along to the group looking for help, support and information, and occasionally to help others. It was surprising to find that most people had very limited information about the group before they went. This seemed to be the case whether or not the group had leaflets, or was professionally supported. Thus people looking to a self help group went along with expectations that they might be put off by "cancer patients" who were old, and visibly ill. They were uncertain about the group organisation, but some thought they might have to participate, and imagined it like a psychotherapy group. Most thought that the main emphasis would be on cancer itself, and this made them a little uneasy. Most were not sure what the groups' relations were to the formal services, even where a social worker or a nurse had introduced them to the group. This suggests that people are quite determined when they go along to a group, and are willing to face up to some of their worst expectations in seeking out some help and support for themselves. Fortunately most of their worst expectations are not fulfilled, but it does suggest that groups have a poor public image that does not match up to the reality of what they offer.

Each group in this study seemed to attract people by particular routes. Thus the city groups were most likely to use the media successfully, while rural groups rely on personal contact predominantly. Most groups distributed leaflets about themselves to the various health centres and hospitals where potential members might see them. It was only in the professionally run group that several members were there by anything resembling professional referral. In that group the social workers, and less frequently the specialist nurse, encouraged women into the groups. There were no instances of medical referrals or recommendations into the group. In one instance a clinical psychologist had referred someone into a group he was

personally familiar with. This perhaps exemplifies the relationship of the groups with health professionals. The group was something independent that the professionals had no control over and could not take responsibility for. It was therefore difficult for them to recommend self help groups.

Many people who remained in the groups had gone along to the groups for meetings that were predominantly social. Most of the groups had meetings that focussed on interaction between members as well as a more structured program of events. This suggests that these people had a good enough experience at that meeting to continue contact with the group. However, it is impossible to say from these data whether people who attended other types of meetings did not come back. The importance of the initial contact with the group was recognised by the groups themselves, and all developed particular means of making things easy for new members, from a befriending system at the door, to organising meetings specifically geared to new members.

The groups, therefore, emerged as individual dynamic entities that were fluid in their response to the demands made upon them and willing to learn and to change. They were therefore hard to define, and to categorise adequately. They saw their prime role to be the helping and support of each other, and developed informal networks within the group itself to do this. They were keen to develop and move on, and to keep attracting new members. They worked hard at their relationships with professionals, and definitely saw this as intrinsic to their survival. They did not wish, nor did they imagine being able, to survive without some contact with professionals in their area. Some, as has been seen, were better at defining and managing this relationship than others.

DEFINITION AND TYPOLOGIES

DEFINITION

The definitions offered in Chapter 1 will be reviewed in the light of the current data, in the hope that the complexities of these self help groups enrich future definitions of self help.

Many of the definitions offered included an assumption that the groups were problem focussed, and this view was commonly held by members. This work suggests that people come along to a self help group with a wide variety of problems, and that many of these were somehow met within the group setting. Although there may be a commonality in people's experience, what they personally find difficult did vary. In addition the groups were unlikely, either as organisations, or as individuals, to articulate 'a problem' as the focus of the group. They were much more likely to talk about what they got out of the group, ie support, practical information, social contact etc than to say the group was *about* cancer. This may be a particular aspect of these groups, and would need clarification with another population. The groups define themselves as support groups for people with particular experiences (the

diagnosis and treatment of cancer). If anything they might define the problem as adjustment to those experiences and the emotional isolation associated with it. This, for them, includes making sense of the medical process, and, because they are likely to continue to use medical services, negotiating a different way of relating to them.

Groups have also been seen as fulfilling an unmet need. The groups studied here were often aware that they were fulfilling a need that was not being met elsewhere. However they were not always critical of formal services because of that. In both locations specialist nurses were in post, and in Manchester social workers had been appointed with a particular remit to offer help to people with cancer. The groups saw themselves as offering a different *type* of support, and in a different way. They were able to see the uniqueness of sharing experiences and moving out of the professional - patient roles. Thus it was not so much the problems that were unique, as the method of dealing with them.

Thus the emphasis was on shared experiences, an aspect of self help intrinsic to most definitions. Looking at this in more detail here has revealed how different those experiences were. Many of the people in the groups had widely different experiences, both in terms of diagnosis and treatment, family and social support and in personal coping. They were not a homogeneous group. In some groups, there were also people who did not share the experience of diagnosis and treatment for cancer, this included relatives and friends. In one group the membership included volunteers who had become involved in the group through offering practical help to the group in the first instance. So the groups were able to function in such a way as to mix both helpers and helped, almost regardless of experiences. Their adaptability is also suggested by their accommodation of the researcher in a participant observer role.

The emphasis placed on the helping relationship, and the 'helper principle' was less evident in the groups as the literature would suggest. Although it could be said that the majority of people in the group were both helper and helped, there were some people in the groups who, at least at the time of the study, remained predominantly in one of those roles. Some people were defined as members of the group who came along only to specific meetings to listen to speakers and who interacted minimally when they were there. Others spent a great deal of their time in group related activities, and presented this as of little benefit to them personally, and for some it was at a cost. It could be argued that the latter were indeed benefiting at some level, or indeed in one instance using the group activities as a form of defence. Many of the people interviewed did not see themselves as doing much in the group. It was only after some consideration and prompting during the interview that they came to acknowledge that their participation when it was at the level of making tea or in talking with others. Many had not considered this as helpful to the group as a whole. Thus although the helper principle, where the helper is benefiting as much as the helped and those roles are shared, was evident in the groups, it was not often recognised by 'ordinary' members. Its influence then, on self help groups is not as obvious to group members as it may be to others. It is possible that this is an

issue in this study that relates more to gender and illness than to self help groups per se. Further research with different groups is required.

The construct of serial reciprocity (Reissman 1965), where those who have been helped stay on and then help others, did not always work smoothly in the groups studied here. Indeed the notion that at one stage someone is in need of help and then later returns that help did not fit easily into the groups' functioning. In many instances the need and ability to give or take help changed in an often undefinable way (eg illness recurrence, changes in social circumstances, personal adaptation etc). Thus the course through the group did not move smoothly from one (being helped) to the other (giving help). There was some evidence that 'older' members helped 'newer' members in this way, mainly in terms of settling into, and feeling comfortable in the group. The data from the follow up interviews in particular, indicate that people who stayed in the group for extended periods, did take on different roles in the group and gained confidence. In the group that had the most professional input (E) there was expressed concern that the serial reciprocity did not happen. This may have been a function of having professionals in the group who were fulfilling the role of 'older' members. Indeed the professionals and the women in that group specifically saw the social workers part as 'for continuity' (see p 161).

The actual organisation of the groups, and less frequently relations with professionals are used in the literature as part of the definition of self help groups. Predominantly groups are seen as self managing with the main beneficiaries being members themselves. In the groups studied here, several were influenced in their management by professionals rather than group members. The organisation of the groups was invariably linked in with the start of the group. In all but two of the groups professionals were involved then at some level. The two groups who 'started' without professional involvement both actually emerged from one (and the same) fading group. One group later became affiliated to a national self help organisation, and the other started to negotiate relations with professionals. Of the other groups, two were 'helped' by professionals at the beginning, and the others were organised by professionals in from first instance. So to say that self help groups are self managing may not reveal the intricacies of their organisation. This will be dealt with in more detail in the section on relations with professionals.

Linked into the organisational definitions of self help groups it had been mentioned (Knight and Hayes 1981) that they are non-profit making, and that they do not use outside funding. The groups in this study seldom had a strong economic focus, however they were concerned to maintain themselves financially (see p 183). They did sometimes make a profit from their fund-raising activities, and used it within the group, or occasionally donated money to other organisations. Two of the groups actively sought outside funding from local councils and others sought economic support from local businesses. Although the making of profits was not the major reason for the group, they did need funds for their development, and

accordingly sought these out. Where groups approached formal agencies for funding, they were cautious about how this might affect their functioning. For some, it meant that they had to change the format of the group and develop the usual 'office' of secretary etc, in order to qualify. This perhaps exemplifies how much this particular group (D) attempted to follow a strong self help model, and were frustrated from their attempts by the reality of struggling to develop.

It was noted in chapter 1 that self help groups' relations with professionals was seldom used as part of the definition of self help groups. Those authors who did look at this felt that groups had little to do with professionals and that the relation between them was uneasy. This study suggests that to ignore groups' relations with professionals is to view them in unrealistic isolation. All the groups in this study worked hard at maintaining reasonable contact and relationships with professionals. They include them in many ways and made the maximum use of those contacts to legitimise the groups. The groups were realistic in their recognition that they could not, and indeed did not wish to, exist without contact with professionals. However, that contact was not without its difficulties, as will be seen later. One major difficulty in the literature was the assumption that groups could make any other choice anyway. The groups in this study felt that they had relatively little power in determining their relations with local professionals, but what they did have they used. They did so in a context where professionals had often not considered the nature of that relationship, but had assumed it would follow the usual model of professional / patient.

Thus the definitions of self help groups as offered by the literature reviewed in the introduction to this work can now be revised. Assumptions about the focus of the group, its organisation and activities are all rather more complex than was suggested. In particular to omit a consideration of groups' relations with professionals is to ignore a rich and influential area.

Finally, we should consider whether self help groups, by definition, hold an ideology of change. Although groups in this study may have helped people change through helping them cope, their main focus was seldom to challenge and change the services provided, or society in general. They were not active as pressure groups, although they did act to try to influence attitudes of professionals rather than their clinical practice. They were keen to influence new modes of working that would facilitate communication and the exchange of information. This they managed through their relations with professionals, and, in the groups, provided a forum for dialogue. Whether they can be held a part of a social movement is still in doubt. However, with the ensuing policy changes in the NHS, this may be an area to keep under closer scrutiny.

TYPOLOGIES

The way in which the groups studied here do not fit comfortably within the typologies offered in the available literature has already been commented on in the introduction. Taking each in turn suggests that these groups often fit into several of the types offered. One such

example is that offered by Levy (1982) of physical difficulties, mental and emotional difficulties and groups typified by their emphasis on social status. The groups in this study could be said to have come together, to some extent, because of physical difficulties (illness) but it was not the actual physical difficulties that they were predominantly concerned about. As the groups could be seen to offer emotional support, they could also be included into the second category, and as some people felt that their social status had changed, at least in a personal way, they might also fit into the third type. Thus this typology cannot be used to unambiguously assign groups to one and only one category.

Similarly with a simpler typology offered by Sagarin (1969) who divides groups into those that challenge and those that conform to society, it can be seen from the data presented here, that these groups do both. Although they do not present an overall challenge to society as a whole, their existence is often interpreted by professionals as some sort of challenge to their autonomy. Thus one of the main thrusts from some of the professionals in this study was to co-opt the groups, as they were seen as being outwith and therefore potentially challenging. At the same time, it is clear from the data presented here that the groups went out of their way to encourage good relations with professionals. They made clear statements about their aims and activities that clarified their social and supportive role, and emphasised that they did not advise or interfere with medical management. They supported professionals in their clinical work, and could therefore be said to be conforming rather than challenging.

From the data in this study it would be of little use to offer an overall typology of self help groups based on only six groups with a narrow health remit. However, the data are sufficient to throw some light on how relations with professionals might be improved which may provide some basis for a future typology. This, of course, would have to be extended with data from other groups in different areas. Nevertheless these data are still sufficient to cast doubt on the typologies put forward by others, insofar as they exhibit elements of supposedly 'distinct types'. Moreover, they also raise questions as to whether "typologies" are a useful means of understanding the phenomenon of self help groups. Typologies carry with them a suggestion that the range of groups can be classified into mutually exclusive and exhaustive categories. As has been argued here, such classification does not characterise even the small number of groups studied in this work.

RELATIONS WITH PROFESSIONALS.

This work traced the development of the women's health movement and linked it in with the development of self help groups. This was done on the basis of their shared concern with the social and personal dimensions of health and health care delivery. It was noted that the participants in the women's health movement came up against opposition from professionals on several levels. The aims of self help groups were seen to be somewhat different from that of the women's health groups. The latter were offering a direct and vocal challenge to the status quo and attempting to change and in some instances supplant (or take back) elements of their

health care from professionals. Self help groups, in Britain at least, were less likely to offer that direct challenge, but more likely to aim to work alongside health care professionals to achieve an optimum health care outcome. This work suggests that the groups studied here were very concerned to have good working relations with professionals, that they did not wish to supplant anything that was already available within that service. What they provided for themselves was not, and indeed may never be, by its nature, available within a formal health care set up. Nonetheless, the self help groups were poorly understood even by some of the professionals working with them, and they were actively excluded from any participation within the formal services on any terms except those specifically dictated by the medical profession.

Taking Killilea's (1976) conceptualisation of groups as working within, next to or opposed to the formal services, it will be seen that the groups activities in this study fitted into each. They could be generally categorised by their predominant relations with professionals and, ergo, the system of professional services within these three broad categories. But a more detailed analysis of their activities suggests that this classification is not watertight. First, their relationship moved dynamically between these categories. Whatever position they took in relation to professionals and formal services had disadvantages and drawbacks which will be summarised here.

To summarise the position taken by each group in turn. Group A started along with professionals although mainly self determined. They continued to operate in that mode, and maintained on-going relations with a specialist nurse, who remained essentially outwith the group.

Group B started with no professional involvement, emerging from another group. They more or less continued in this way, affiliating themselves with a national self help group. They maintained good relations with professionals, but had less close links than group A.

A specialist nurse prompted the start of group C, so that could be seen as being 'within' formal services. However, she, and the group members, constructed the group as falling alongside professional services. This was an interesting dilemma, but highlighted the position that professionals involved in self help often maintained ie. an uncertainty as to whether the self help group did or did not constitute a recognised part of their work. So although this group (C) started 'within' the services, and to a major extent was maintained by the input from the specialist nurse, it operated along side those services. They also were able to be fairly critical of service delivery, but never worked in opposition to professionals in the area.

Group D emerged from the same source as group B, and thus started without any professional input. However, during the time of the fieldwork, this group worked along with professionals, was involved within the professional domain, and also provided services that were outwith that available in the formal services. They encompassed all the possible positions

in their attitudes towards professionals, but did not actively work in opposition to formal services. It was one of the groups that developed most rapidly and remained one of the strongest.

Social workers started group E, as a specific interpretation of their job remit. The group was initially set up on an experimental basis, and continued although the initial promoters were replaced by other workers. The group remained strongly led by the professionals, despite their attempts to move it more towards self management. Thus it started and more or less remained 'within' the formal services, although much of its activity was 'along with' those services. Thus the group was never run by the women themselves, and the program of activities was evolved in co-operation with the professional workers. The differences between this group, and group C, which was also started by a professional worker, was the degree of autonomy and organisational independence the people in the group assumed. It seemed that group C would continue, with or without the professional, although she was a very highly valued member of the group. In group E the women actively resisted taking on more responsibility for the organisation and running of the group.

Before the start of group F, the main impetus came from one person who for a year held a series of meetings with professional workers with a view to starting a support group. He became frustrated with the slowness of the process and on his own impetus went ahead and organised the first meeting of what was to become the self help group. So although this could be seen as an initiative that came from 'within' the formal services, it was actually started almost 'in opposition' to the professionals. Interestingly the group aimed to work along with professionals, and did so very well. They, like group D, encompassed the full range from 'within' to 'opposed to' in their activities and attitudes. They also were concerned about issues of autonomy and control, and wanted contact with professionals on their own terms. They also applied for, and achieved outside funding. While at the same time attempting to maintain their self help emphasis, they knowingly compromised some of that in order to fit in to the formal services, and therefore obtain grants etc. Again none of their activities were opposed to formal services, but their determination to maintain their autonomy as a group meant some conflict with professionals with little understanding of the nature of self help.

The benefits for the groups in their contact with professionals were mainly in terms of legitimisation. In essence the groups could not exist without some support, however little, from professionals. So it was not necessarily a choice for them, but more a case of finding professionals sympathetic to their aims, and co-opting them. The groups had to convince professionals, funders, etc that they did have something to offer that was acceptable to them, and not threatening to them. They had relatively little power in determining this relationship. They were keen that professionals should act to support the group, without taking over. The groups who best managed this were those that made clear statements about the nature of their group and their determination to maintain their self help status. Thus groups C and F

articulated this and at the same time co-opted a wide range of professionals into consultancy, advisory and collaborative roles, despite the fact that they started with very different initial contacts with professionals. Other groups also managed this, but never so well. It appeared that when a group was clear about what it wanted professionals to do, and was able to enter into a dialogue about that from a strongly understood position, it achieved the optimum relationships. In other words, where the self help group was able to let the professionals see exactly what their role might be, this made it easier for all concerned. The position taken by the most successful groups (ie those that were happiest about the way they related to professionals, and who felt that they did not unwittingly compromise their self help stand) was that the group ran fairly independently, but not in antagonism to the formal services, and that professionals were people with particular expertise, and group members had their own area of expertise. The professionals involved in these groups were also generally clearer about the role of the group and their own position in relation to it.

For those groups that were initially led by professionals, in one (group C) the professional herself had clearly articulated this boundary from the start. In the other (group E) this had not been done, and the relative responsibilities of professionals and participants was unclear and later difficult to change. The group members and the professionals seemed to find it almost equally difficult to change their respective roles from professional / client to co-worker.

Thus the way the groups start, and their clarity about their aims and the relations they wish to achieve with professionals seem to be crucial. These data suggest that once these are established, it is quite difficult to shift them. This finding may be particularly influenced in this study by considerations of gender and/or illness, and further work is needed to establish whether it generalises to a wider context. It is always going to be difficult for groups starting off, usually in a fairly tentative way, to articulate these issues. It is also an erroneous assumption that they are able to wholly determine their relationships with the more powerful professionals.

For professionals the difficulties seemed to lie in their inability to adopt a different way of working, and to relinquish professional control. It seemed to be difficult for many professionals to see people behaving autonomously, even though that was taking place essentially in their private and social lives. Because there was a health and illness issue there, professionals often felt that they had to remain accountable.

It is perhaps difficult not only to ask professionals to relinquish what they have been taught and socialised into, but also to expect them to do that as part of their job. It was interesting that some of the professionals interviewed here saw their work with the groups as something that took place outwith their professional work time, and perhaps therefore, allowed them to step out of the professional / patient role.

One of the main focusses for the group in their interactions with professionals was not only their survival, but their validation and legitimisation. This is dealt with extensively in chapter 7, and will only be briefly summarised here.

The groups were never wanting to work within the services to the extent that they lost their autonomy and direction as separate entities, but they were keen to work closely with the services that they themselves, as individuals, had (on the whole) benefited from. Many had to learn that they had to clearly define their own parameters, and their own functioning.

As the fieldwork progressed one recurrent caution was to 'not step on anyone's toes'. In addition to this, the groups were keen to co-opt good contacts with professionals. One of the main ways groups did this was by managing of information. They clearly and repeatedly stated that they did not deal with medical issues, and defined their role within the psychosocial dimension. They were at the group to talk about their personal experiences, and to put those into context. Any medical management was clearly in the hands of the health professionals. Health information that the group wanted was sought from a professional source, with speakers contributing to the groups, and also legitimising the group by doing so.

Even the most minimal contact, like a half hour talk, served to help the public image (and the internal image) of the group. The professional's name would appear in the program which would be distributed widely. In addition some professionals were co-opted to lend their name to the group, as a president, or honorary head. This was usually accomplished with some ease on both sides.

In addition, many of the groups sought more formal training or back up from professionals. This was mainly done by those groups who were more active in their helping. Those who ran a phone line had training for that and the support of a variety of professionals. It seemed to work well.

However, the process of legitimisation does highlight the emphasis that groups placed on their relations with professionals, and the inequality in that relationship is often forgotten. The groups did not have any real choice in whether or not to negotiate, but they could have some influence on how. It would be interesting to repeat this type of study now, some years later given recent government changes to apparently empower people to have more say in their own health care. Maybe the balance of power has shifted, even a little. Certainly at the time of this work, the group members felt that they could challenge the professionals only at their peril, as they were dependent on them for health care. As noted earlier, it is not possible, without further research, to determine the extent to which this is an issue that relates to gender in this instance, or disease.

POLICY

Information from this work falls into two main categories in relation to policy. Firstly policy changes that might arise from data about women's experience in the diagnosis and

treatment of breast cancer; and secondly potential policy recommendation more directly related to self help itself.

It is clear from these data that women were less likely to have major and personal difficulties with the medical and technical aspect of their diagnosis and treatment, but problems arose in relation to the way they were informed about these processes. A strong need for clear communication and some degree of psychological and social support was evident. In recent years this has been recognised within the provision of the service with much written about it (see Fallowfield and Clark 1990) as well as the appointment of specialist nurses. However, these nurses cannot work well without adequate training, nor should they do so in isolation. The provision of a support service to women, and to other staff, is to be recommended. There are still very few treatment units that have easy access to psychological and psychiatric back up.

In addition educating staff to be aware when some women may experience extreme distress, either at the time of diagnosis and treatment, or later, would be helpful. This study suggests that women may cope well while within the hospital and immediately after, but experience a major adjustment reaction upon returning home, and some months later. The follow up appointments, which are generally medical in nature, could also serve a screening function for psychological morbidity. This may also be something that self help groups could be involved in, and that would help professionals and groups to work together.

This study suggests that self help groups provide a unique type of psychosocial support. Whether this will be acknowledged within recent policy changes has yet to be seen. They do not have a wide or a loud political face, and there is a danger that they will be ignored, or subsumed within voluntary groups. As they themselves seem to be tentative about maintaining a high political profile, this may be something that professionals could help with. But professionals, as has been seen in the above sections, do need to re-educate themselves about the nature and function of self help.

To articulate a global policy in relation to self help groups would not be helpful. This work suggests that they are a local response and have to negotiate with local services and personalities. However they might be advised to pay particular attention to articulating their own aims and agendas in order to avoid being misunderstood. Once this is clear then they can both defend their position (ie as a social not a medical phenomena) and allow for flexibility.

Groups should also pay attention to their own organisational structures, and how they are to be managed and fulfilled. In particular, the groups studied here developed their own policies on attending to new members, recruiting new people, the range and level of participation as well as the timing and frequency of their meetings. They found it useful to balance the informative and the social and supportive elements of their contact.

It was also useful for groups to liaise with other groups, and thus share their resources and information. In addition this is to be recommended as a way of maintaining support for the

groups as a whole, and particularly for more active members. This structure, of liaison between groups, exemplifies, at a macro level, the principles of mutual aid.

Where groups are able to get together, that can also help each other with maintaining relations with professionals. This is a particularly important area with the advent of community based initiatives (Working for patients 1989; Caring for People 1990). Policies might be recommended to enable professionals to work with groups of this kind with emphasis on finding out about individual groups and how they function. In addition, professionals should be helped to be more aware of the issues of power and control that might affect relationships between self help groups and themselves. A further emphasis on communication and acknowledging expertise would also be helpful.

Professionals should be made aware that these groups present a possibility of a new model, which is primarily social in orientation. The possibilities of the groups working within, next to or opposed to services should be made clear, as well as the realistic likelihood that the relationship will be dynamic. Professionals could be made aware of their input to the groups in terms of the type and amount of input, while maintaining their own expertise.

Thus most of the policy recommendations emphasise acknowledgement of self help as a potentially important and useful aspect of health care, and facilitating the means of encouraging that.

FURTHER STUDY

The richness of the data gathered here justifies the methodology used. No other means of accessing people's experiences would have been possible. However, the very wealth of the data proved a drawback at times. Any future study in this area might consider concentrating more closely on the specific interactions of professionals and groups, and perhaps shadowing this contact over an extended period of time to clarify the process of legitimisation and the negotiation of relationships. Given that this study has shown that relationships with professionals are a major part of self help functioning it is worthy of further study.

Further information about the groups and who does and does not attend might be clarified by charting every group meeting over a period of time, and identifying new faces, and the subsequent contact with the group. At the moment it is impossible to say what proportion of people know about the group, or attend. It might also be interesting to follow up a cohort of women, to see what they do for help and support in addition to, or instead of attending a group. How women deal with the everyday worries and concerns following diagnosis of breast cancer is still not a well understood area. If it was clearer, then health professionals might be able to offer more appropriate interventions, which might, or might not, include promotion of self help groups.

In summary this study suggests that self help groups have both benefits and drawbacks for members. Professionals might remain open to the possible benefits for themselves, both in identifying groups as an excellent educational and possible preventative forum, and also a means of gaining a better understanding of the treatment process. They are then at liberty to use that knowledge to modify their own clinical practice. Both professionals and group members should recognise that the relationship is unlikely to be straightforward and professionals need to adjust their training to allow them a social view of health, and to value non-technical expertise. They might then be encouraged to try and work outwith the tight constraints of professional practice, and make their own assessment of local self help groups. They can then consider offering practical help, facilitating entry into the group, or acting in a consultancy or training role. In turn the groups need to recognise the skills and limits of professionals. They should be aware that there are both benefits and possible drawbacks in encouraging professionals' involvement. The groups need to recognise their own unique contribution and to value that, and legitimise their group in its own right.

Given the growing importance of health promotion and self help, there is increasing recognition that a more efficient partnership is needed between health professionals and the wider community. This study aims to contribute to our understanding of the importance of self help health groups for promoting the health of people who have been affected by a life threatening illness and the continuing need for support by health professionals of these groups in a way that sustains them and promotes their autonomy.

APPENDIX I GROUP VIGNETTES

This appendix contains further details of the types of meetings and activities of each of the groups involved in the study. Information is presented in the body of the text (Chapter 4) about how each group started and its first meeting. Details are given there about the group's current structure and its interactions with professionals. Again, care has been taken to keep the groups anonymous, but group members and local professionals will be able to identify the groups from the information given. Anyone identifying a group is entrusted to keep sensitive information confidential.

GROUP A

This was a breast cancer group set up and run by members with some input from local professionals. It was still in its first year of existence at the time of the study.

MEETINGS

1. Monthly support and information meetings.

These meetings were held on a regular day each month in the evening in the halls of a community resource. Speakers would be invited to talk about a variety of cancer related topics, with an occasional non-cancer topic at intervals. The format was a short time for talk and introductions at the beginning, then the speaker, who determined their own format, followed by tea and biscuits. The latter allowed the women to spend some time together and to gain support from each other as well as to discuss that month's topic.

These monthly meetings were advertised in the leaflet that the group produced on a two or three times yearly basis. Exceptional meetings, where an important speaker was invited, might be advertised in the local press.

Initially there was no structure for welcoming women into the group, so that new members were only randomly spotted by more regular members. This issue was addressed by the group towards the end of the study period.

2. Weekly Drop-in Centre.

The group gradually took on the option of providing a drop-in centre once a week in the mornings in the premises of a prosthesis company. The company donated the use of a room for this purpose, and required no return from the group. The premises were based near the city centre, and the group members took it in turns to be there. This resource was not well utilised by other members, although it attracted a few new people who went along there instead of to a monthly meeting as their first contact.

It was often at this weekly get-together that the group was discussed by the key members. Issues of publicity and funding were sorted out here on a regular basis.

3. Committee.

The committee of seven members met only once a year to elect offices and plan the format of the leaflet and monthly meetings.

OTHER ACTIVITIES

1. Hospital Contact.

The group was keen to establish contact with the breast treatment unit, and did arrange to start being available there on a regular basis after the end of this study. No information is therefore available on this.

2. Telephone Contacts.

The leaflet that the group produce included the home telephone numbers of three of the women in the group who agreed to be contacts for the group. This seemed to be used only infrequently by new members.

The group member kept in touch with one another to varying degrees, and not on an organised basis.

3. Finance.

The group was self financing at the time of the study. It did receive a small grant of £100 as a one off, from monies donated for that purpose and administered through a local surgeon.

GROUP B

This was a rural group which included both women and men. It was a general cancer group but had a strong orientation to women with breast cancer who made up the majority of the membership. It was affiliated to a national organisation and had very little input from local professionals. The group had run for just over three years at the time of the study.

MEETINGS

1. Monthly Meetings

The group met on a regular day each month in the evening. The format for that meeting varied to include invited speakers from within and outwith the group. So professionals might be asked in, or else a member might talk about something that was important to them. At other meetings there was no organised speaker, with the explicit aim of allowing members to spend time with each other in the group setting.

It was notable, in the intimate small group setting, that most people in the group contributed in some way, whether it was handing around the home baking, or recommending a book.

2. Committee Meetings

The group was obliged, through its contact with the national organisation to hold a yearly committee meeting. This was done according to the prescribed format but in a very relaxed, unofficial way. It usually formed part of a social/support focussed monthly meeting, so that regular attenders were there already and did not have to make a special effort to attend a committee meeting. This also served to de-mystify the notion of a committee meeting.

OTHER ACTIVITIES

1. Hospital contacts / home visits

The group did not have a policy of providing a service to a hospital, but they did visit group members if they had to be in hospital. In addition, because of the small community, if anyone was due to attend hospital, one or another member of the group would know about it purely through social contacts. In such cases the message was passed onto them about the group, and that person was encouraged to ask for a hospital or home visit from a group member. In this way the group made contact with most people who were facing a possible diagnosis of cancer in the community.

2. Telephone contact

Although some of the group members did keep in telephone contact with each other, this was usually during times of crisis or difficulty. The more normal contact was person to person in people's own homes.

3. Finance

The group did receive a small stipend from the national organisation, and its funds were monitored through it. They organised their own fund-raising activities that were generally very well received and they were never short of money. They did not have many experiences, as they met in a members house. Postage was the most costly item. The group would make occasional donations to local causes, eg contribute to a new piece of hospital equipment, and this was discussed and decided at group meetings.

GROUP C

This group was situated in a small town. It was run along self help lines, although it had been initiated by a local nurse who maintained a key role. It had been going for two years.

MEETINGS

1. Monthly Meetings

The group met on a monthly basis in the evenings in a small church hall annexe. Around 7-13 women attended. The program, true to the original emphasis of the group, included a wide variety of topics from a talk from the Medical director of the Breast Screening Unit, to skin care and dry flower arranging.

The meetings were arranged so that social events were included, and times were set aside for "Chat Night".

The basic format for each meeting included a short time for talking amongst members before the speaker arrived or gave their talk. At this time any group business would be discussed, and if necessary time allocated after the talk for further discussion. This was followed by the main event, and then by discussion, tea and home baking (all provided by members), except the cup which you had to bring with you.

At the group meetings women also took the opportunity to talk to the nurse, who was nearly always there. This seemed to be an access arrangement that worked fairly well for all concerned, and indeed was an important function of the group.

The group was small, and friendly, and most people knew each other before they came along to a meeting. The newcomers would have usually had contact with Frances or with one of the other group members. A separate meeting was not set aside for new members, but each newcomer was greeted by someone who knew them and who generally looked after them for the first meeting or so. Because the group was small and informal, this worked well.

There were no meetings set aside for group members to discuss their own experiences within the group, this was not seen as part of the group function. The group maintained a high social element.

2. Committee Meetings

Initially the group did not want to have a committee but eventually felt they had to. The meetings were carried out in an informal way, but separately from the usual monthly meeting. All the women were encouraged to attend, and quite a few did so, particularly the nucleus of usual attenders

OTHER ACTIVITIES

1. Hospital Contact

The group would visit group members on request. Two or three members also volunteered to visit people in hospital and at home

2. Telephone Contact

Many of the women kept in personal contact between meetings. Two or three members publicised their telephone numbers on the group leaflet, and were occasionally contacted by potential new members.

3. Finance

The group was self financing, from a variety of fund-raising activities within and outwith the group. They held bring and buy sales, small raffles etc. Their financial need were not great, and this sufficed.

4. Leaflets

The group produced a newsletter that gave updates on programme and things of interest to members. It included poems, recipes and personal experiences of helpful hints. This is distributed to a lot more people than attend the group.

In addition the group produces a series of leaflets about prosthesis, swimwear adaptation and clothes. This reflected the skills of dressmakers in the group, who had adapted dress patterns for their own use. These were essentially informative and educational, and produced with the mastectomy nurse.

After some meetings the group produced a leaflet about that meeting, eg. after a series of questions and discussion about prosthesis, this was written up and distributed. In this way women had some educational material, that was also available to people outside the group. This mingled with sheets about drying flowers.

GROUP D

This group met in the city and was initiated and run by members and expanding rapidly. It maintained co-operative relations with professionals. It had moved from a cancer group to include people with chronic pain and had been going for three years.

MEETINGS

1. Main meeting

This took place on a regular evening each week, and was open to all members. The group placed great emphasis on group support, and although they did invite speakers along to meetings, this was fitted in and around personal contact.

During the fieldwork the location of the weekly meeting changed from the Women's Health Shop, to community education premises. Shortly thereafter it was located in the city centre premises that the group managed to procure.

2. Second Saturday Meetings

These meetings were arranged once a fortnight, and were fairly informal. They were held during the day in N's house, and allowed people to get together on a more relaxed basis. They were also the meetings that introduced new members to the group, rather than the organised formal meetings.

3. Drop in Centre

The group members organised a regular drop in centre during the day, three afternoons a week. They had fairly inadequate premises for this initially but persisted nonetheless, and the centre was eventually moved. At these times people could get together on an individual basis to talk. Also a variety of activities were organised eg art expression, relaxation etc.

4. Monthly Spiritual renewal meetings

These were organised at the request of members. This was ecumenical and open to non-believers. Prayers were said for those requesting them, but each meeting was individually shaped by those present.

OTHER ACTIVITIES

1. Hospice

The group maintained good regular contact with the hospice on a mutually beneficial basis. The group learnt quite a lot from hospice staff, and were supported by them in their endeavours. Also the hospice staff seemed to be helped by talking to the group members, and welcomed their input when members were staying there.

This group was unusual in its explicit inclusion of death and dying on the public agenda. Deaths were reported in the brochure, and they stated their willingness to meet the needs of members approaching death, as well as support for relatives.

2. Telephone contact

The group had two and then three members' numbers publicised in their information leaflet. Some participants stayed in regular contact with each other, although this was on an informal basis only. The main burden of telephone support fell to N-- and S---A--, and at times was clearly over-much. This eventually was moved to the centre, which had an ansaphone.

The Chair and the Secretary of the group recorded their activities over a year, and they took 907 calls about the group. They made 832 calls. These were only those made outwith the actual centre, and therefore under-estimate the groups' activity in this area.

3. Home visits and Hospitals

The group maintained a list of people willing to do visits. However there was a stated policy of not visiting on request, except where people were already members of the group. In those cases the visits were on the basis of 'friend' not as an agency. Altogether the Secretary

and the chair recorded making over 200 visits in the year. This, of course, does not include visits made by other group members, of which no definite statistics were available.

4. Branches

By the end of 1985 there was an established branch in E-- C---. Further branches were en-route for further afield in Scotland, but were not yet fully operative.

The branch modelled itself on the original group, adopting its constitution, but raised its own finance.

5. Finance

The group was initially self financing, with the help of Trusts. They were seeking funding from a variety of sources, often with disappointment. Thus they were invited to approach the social services for money, which they did not get. But they were awarded a small sum of money in 1984 from social services. They also applied for a variety of monies to allow development into city centre premises and to employ staff. Thus by Sept 1985 they had applied to L-- Health Board and its joint funding, Community Care and Support Scheme, to Hospital Endowment Funds at four hospitals, the Social Work Services Group under Section 10 of the Social Work (Scotland) Act. They were also being considered under the Unemployment Voluntary Action Fund administered by the Carnegie Trust.

Some of these came to fruition, but mainly fall outwith the time of this study.

The members did some fund raising themselves eg a mini- marathon, and gave various donations.

The expansion of the group was a bit of a double edged sword with the group. Although they did want to expand and help more people in more ways, they were aware of the potential compromises that funding could bring with it. In particular they were keen to protect their autonomy and ability to self govern.

6. Volunteers

This group was unusual in its interactions with volunteers, who did anything from cut the grass, to drive people to and from meetings. The volunteers were seen as special 'members' of the group, and a few of them became more involved in the group. The transport volunteers were organised by one of the group members, and provided a means by which disabled people might attend meetings which would otherwise have been impossible.

7. Training

The group would argue that they were always learning by attending meetings, but they specifically arranged for members to attend training events as appropriate, eg one member went to a course on 'Using Micro-computers', five members attended a seven week training course on improving counselling skills. thus they were interests in gaining information as well as skills.

8. Future

In 1985 the main focus for the future was to expand the group nationally. This was already underway with the first new branch opening that year.

In addition the group intended to set up a short stay home for respite care, feeling that two or three weeks residential care with the support of the group would be very helpful in some situations.

GROUP E

A breast cancer group set up by professionals to run along self help lines. It had been going for 2-3 years, and the workers were looking to make structural changes to move it towards a firmer self help model.

MEETINGS

1. Monthly Meetings

A regular monthly meeting was held in social work premises in the evening. At least one social worker was there, and more often than not the mastectomy nurse. Regularly about 10-15 women attended. These meetings were organised usually around a speaker, or else a topic (eg bras). In the latter the women were encouraged to participate with their own experiences.

The meetings generally took the format of an informal chat time, followed by the main activity, then tea and biscuits before ending.

There was an articulated policy for new members, where they were met at the door by a more experienced group member, and made welcome.

2. Committee Meetings

Despite the professional workers attempts to engage the women in the committee, this was still a rather turgid area. The women seemed reluctant to take on organisational tasks. Thus the committee meeting was poorly attended, and women expressed reservations about attending, in case they got 'roped into' doing something. The members of the committee tried to resist this view of it, but with limited success. This difficulty was being addressed at the time of the research.

OTHER ACTIVITIES

1. Telephone contacts

Three or four of the group members had their name on the leaflet that described the group and its current programme. They were occasionally approached by potential new members. However most of the new members came to the group through contact with the professional workers.

Some of the established group members kept in telephone contact with each other on an informal basis.

2. Finance

The group was largely self financing, with tea etc being paid for through a small charge. They did not pay for premises, and their leaflets were printed through the professionals.

GROUP F

In existence for about three years this group had developed rapidly to include relatives and friends of people with cancer. They had a well organised back-up of professional involved in support and training.

MEETINGS

1. Monthly meetings

The group meets once a month in the evening, and had moved location to the city centre. Up to 30+ people attend these meetings, and there were suggestions that this might be too many.

The meeting are organised so that there is a three point rotation, with open meeting with speaker, informal evening and a meeting focussed on someone's personal experience. These are publicised in advance, and there are no restrictions as to access.

The meetings were organised so that new members were met by two or three volunteer old members when they arrived. Tea and biscuits were followed by one of three formulas. At social meetings the informal contact continued, unless there was an organised social activity. At the other two types of meeting, each person introducing themselves, and some people saying why they were there. This was then followed by either the talk from a professional or from a group member. The group then usually spent some time in informal interaction before the meeting ended. This would include any announcements or group business.

2. Wednesday meetings

The group also met on Wednesday afternoons specifically to share their personal experiences of coping with cancer. These meetings were much smaller, with only 5-6 people in each.

OTHER ACTIVITIES

1. Telephone Line

The group ran an evening telephone service, which later extended to a day time service. The members volunteered for this and the service was well used, mainly by people looking for information and for help with communicating with medical staff. The group members also used the telephone line for contact and support, although they were more likely to phone up another, individual member of the group.

The volunteers were trained with the help of a group of professionals, and support was maintained by the request that all active telephone volunteers attended the monthly meeting specifically organised for them.. At that meeting peer support was offered, as well as critical comment and further training and advice.

2. Drop-in Centre

A drop in centre was eventually opened, with two paid workers. This started towards the end of the study period, and no detailed information is available.

3. Training

The telephone volunteers were selected and trained. This training was done by group members and professionals. The volunteers were also required to attend a training/support meeting once a month while they were active on the telephone line(see above).

4. Funding

The group was initially self funding, but as they moved to setting up the drop-in centre they looked for monies beyond the donations and fund raising events that had previously sustained them. They became a registered charity and money came from a variety of sources, including the University Rag Week. The regional council gave a grant sufficient to fund the centre, and two part time paid workers.

5. Self Help Conference

The group leader set up a national conference on self help groups, and although this took place after the fieldwork, it is interesting to note that this arose from this group.

6. Leaflets

The group produced a more or less monthly basis. This gave programme details and updated people on the groups activities and members. It contained poems, experiences and deaths of members.

Although it gave formal details of charity registration, the leaflet did not emphasise the professional contacts and support the group received.

APPENDIX II PARTICIPANTS

Brief details of the people who took part in this study are listed below. Great care has been taken to ensure anonymity, however should anyone reading this work inadvertently identify themselves or anyone else, they are entrusted to respect the confidences of participants.

The people who were interviewed are listed in alphabetical order. In an effort to protect groups and individuals no reference is made to the group from which each person came. The pseudonyms that have been assumed are to help in the identification of quotes in the main body of the thesis.

Details are given of a brief medical history and, where appropriate, health status of each person. In addition their time in the group and level of participation is noted. In a few instances other demographic data has been included.

Ailsa.

Ailsa had a mastectomy with radiotherapy 18 months prior to the study. She was in her late 50's and had joined the group around a year previously. She took a fairly active part on the clerical side, helping the appointed secretary, having been a clerical worker herself.

Annette.

Annette discovered a breast lump in between her attendance at the breast screening clinic. She had a mastectomy followed by radiotherapy. Her husband was a consultant, she had stayed at home to look after their children. A good friend had died recently of cancer.

Berthe.

Like her husband, Berthe had been a nurse. She was initially diagnosed as having breast cancer 3.6 years ago. She was treated with radical mastectomy plus radiotherapy. She joined the group 3 years ago at its inception and had been an active member for some time. She was well supported by family and friends.

At the time of interview Berthe had received several courses of radiotherapy and chemotherapy following diagnosis of recurrence in her spine and a malignant brain tumour. She died two weeks after completing the interview.

Bessie.

Bessie has a bilateral mastectomy about three years ago. She was an active member of the group, both organisationally and socially. She still had a young, school aged, family. Her humour in the group was greatly valued by the other members. She maintained wide contacts in her own community, along with her tradesman husband.

Carol.

Carol had a mastectomy and hormone treatment 3 years ago. She went to the group as soon as she heard about it eight months later. She was a retired retail manager with family living at a distance. She described herself as 'just a member'. She had worked to maintain her friendships since her separation from her husband some years ago.

Celia.

Celia had a lumpectomy 2.6 years ago and had been in the group a year. She was becoming increasingly involved in the group, particularly in the drop in centre. Unfortunately she had to move from the area shortly after the study period. This move was prompted by her

husband's work in the Forces, which also meant that Celia had less local contacts than some of the other women, but several close and long term friend around the country.

Chris.

Chris was a lively and socially skilled women who had a mastectomy with radiotherapy two years previously. She was in her 50's and had joined the group about 6 months later. Her husband had been a miner and they lived in a supportive, but diminishing mining community.

Chrissie.

Chrissie had breast cancer diagnosed nine months ago and had joined the group only three months previously. She had been treated with mastectomy only, and her physical health was reported to be good. She was fairly socially isolated and took no active part in the group. She did not mention any contact with family, and had not worked for come years. She experienced a variety of mental health problems (which predated her cancer illness) and she took her own life during the year of the field work.

Clara.

Clara had a bilateral mastectomy 20 months previously. Her lymph nodes as sampled at the time were clear although she had diagnosed recurrence at the time of second interview. She has been in the group for about 18 months, and played an enthusiastic part as group secretary. She and her husband had both worked in the local factory, and had lived on a council housing estate for many years with supportive neighbours.

Diane.

Diane had a mastectomy several years ago and had been in the group from the beginning. She played a leading part in its organisation, which increased over the study period. She took on more responsibility for publicity and education. Sue had been in several jobs throughout her life, and seemed very resourceful. She was a skilled administrator, although not formally trained.

Diedre.

Diedre was 44 when breast cancer was diagnosed. She was treated with a partial mastectomy with radiotherapy about a year previously. She had joined the group about 6-7 months ago. She had stayed at home to look after the children, and was now considering re-training. She had previously worked in a shop but now wanted to work with computers. Her husband worked for the local council, and they owned their own home.

Ernest.

After a long history of health difficulties Ernest was diagnosed as having stomach cancer. He was facing many life changes, and became quite involved in the group. He was involved in several voluntary organisations. He lived in a council house, his wife worked part time, but he had not worked, because of health problems for some years.

Ethel.

A retired civil servant, Ethel, after years of benign lumps, had a mastectomy 7 years ago followed by a second mastectomy less than a year later. This was followed by a hysterectomy. Ethel was a founder member of the group and had previously been involved in a group that no longer met. She was a prominent member of her church.

Mrs. Farquar.

In her 60's Mrs Farquar joined the group soon after a mastectomy. She was an active grandmother and lived with her husband who was soon to retire from his job as a lorry driver. Since the interview, she has had a recurrence, and was given Tamoxifen (an oestrogen antagonist).

Geraldine.

Geraldine had a radical mastectomy with radiotherapy to the lymph node 9 years previously following a frozen section. She joined the group soon after it started and had been a low profile member for those 3.6 years. She had previously attended another self help group for two years. That group had ended shortly after her current group got underway. She had an active home life and enjoyed her status as a grandmother. Her husband was in business and they owned their home.

Mrs Hatton.

Mrs Hatton had a mastectomy and radiotherapy 2.6 years ago following the detection of breast cancer through the well women service at her local health centre. She was now 63, and had been in the group for about 18 months. She had initially had some contact with one of the group members, and knew about the groups activities for some time before she attended a meeting. She lived in a supportive community with her husband who worked on the railway.

Heather.

Heather, and her husband Gerry, both professional people, were involved in the group after Heather had surgery for ovarian cancer a year ago. Heather was becoming increasingly active in the group, and saw it as a vehicle to return to full functioning.

Irma.

Irma had a radical mastectomy and chemotherapy three years ago and had been in the group for a year. She was retired from her job as a domestic and lived alone in a council house. During the research period her input to the group diminished when secondaries in her lymph nodes were diagnosed.

Jeanette.

Having had a mastectomy followed by Tamoxifen 5 years ago, Jeanette had been in the group from its beginning. She was an active member, and while thinking of reconstruction at the time of the first interview, this was underway before the end of the fieldwork. She and her husband were "reasonably well off", and he worked in the entertainment business.

Jim.

Jim had malignant melanoma diagnosed 18 months previously, and had been in the group about a year. He was still undergoing regular checks, and was quite ill at the time of interview. His wife kept in touch with the group, but did not attend meetings. Jim had not worked for some time as an electrician, but was very involved in the local church.

Kathy.

Kathy was a capable professional woman with a history of recurrent breast lumps who opted for lumpectomy following diagnosis of breast cancer 18 months previously. She subsequently had an oophorectomy as part of the management of the illness. She joined the

group a year previously and was becoming increasingly active in it. She and her husband enjoyed a particularly close relationship as he moved towards retirement, and their married children settled.

Kirsty.

Kirsty had been a private patient, being treated with mastectomy for breast cancer 14 months previously. She had joined the group four months later and was one of the few people referred by a psychologist. She experienced a depressive episode that was related to events some years ago which was effecting her marital relationship. Her husband was a skilled manual worker. She remained an active member of the group. She was planning on leaving the group at the time of first interview, but had not done so six months later.

Lena.

Lena had a mastectomy 10 years ago when she lived abroad with her husband, a successful and hard working businessman. She had then been a volunteer visitor in a cancer care organisation. She had attended the inaugural meeting of the group, and had been 'roped in' to being a committee member. She was not happy at the time that the group took up, and planned to reduce her input, but had not done so by the second interview.

Lily.

Lily had lymphoma diagnosed 4 years ago. She ran her own business and lived with her husband. Lily was sick at the time of interview, and was awaiting the results of a biopsy. She did recover, and later contributed to the group newsletter.

Liza.

Having been to a public talk organised by a self help group, Liza made contact with her local group there. She had had a mastectomy 3 years previously, and had been in the group for over two years. She had never played an organisational role in the group and felt that her working class background made her shy of groups.

Louise.

Louise and her husband Michael, a professional couple, had coped when their three year old son was diagnosed with cancer. They were actively involved in the group, particularly on the telephone line, which they were able to manage from home. Their son was doing well at the time of interview.

Lynda.

Lynda had been widowed in recent years and now lived alone in her bought council house. She had had a radical mastectomy following frozen section 7 years ago. She also had a course of radiotherapy. She had previously attended another group, and played an active role in setting up and organising the current group. She had a wide network of friends and an active social life.

Mat.

Mat, an entrepreneurial man, had had Hodgkins disease 10 years previously. He was a founder member of a group, and was active in its organisation and running. He gradually reduced this input as he moved into other areas (eg organising conferences). He lived on his own in his country cottage.

Miriam.

Miriam was a professional woman who was one of the people interviewed who did not have cancer. She joined a self help group 4 months previously to help her cope with long term lower back pain.

Nancy.

Nancy had a mastectomy a year previously and had come into the group some six months later. She did not attend every meeting and was fairly cautious in her commitment to it. She had a grown up family and a variety of other interests. She led a quiet middle class life.

Nina.

Nina had a mastectomy for breast cancer eight or nine years prior to the study. She was a founder member of a group, but had attended another self help group for some months prior to that. She was a widow and professional woman. In recent years she has been ill again, and was receiving chemotherapy. She sometimes felt socially isolated, and certainly missed her husband's companionship.

Nora.

Nora had a simple mastectomy with radiotherapy six months ago and had been in the group for two months. She attended group meetings, but was not involved in the running of the group. She had a teenage family and supportive husband. She regarded herself as working class. She was considering reconstructive surgery.

Mrs Norton.

Living on her own since retiring from her professional job, Mrs Norton had a radical mastectomy 8 years ago. She had been in the group since its beginning. She was a capable and active woman who took part in organising the group and played a key role. She held coffee mornings to help with group funds and contributed home baking to each meeting.

Olive.

Olive had a radical mastectomy 10 years previously as a private patient. She had been in the group since it started about 18 months ago. She had been in contact with another more distant group and had been put in touch with the local group through them. She decided to have breast reconstruction and pursued this vigorously during the time of the fieldwork. Her input to the group focussed around this experience, and she received support, in turn, from the group. Her husband was in the construction business.

Pamela.

Pamela was the youngest woman interviewed, being in her 30's. She had a mastectomy two years previously, and was in the group from its first meeting. She had two small children, and lived with her husband, a manual worker. Her health deteriorated during the fieldwork time, and she died less than a year later.

Regina.

Regina had a mastectomy with immediate implant and nipple reconstruction 3 years ago. She had been in the group 7 months, and attended meetings regularly. She was still undergoing reconstructive surgery. Her husband was an administrator.

Sandra.

Sandra had a mastectomy 2 years ago and joined the group soon after. She had chronic chest problems (TB) which also affected her health. She was on the group committee, but said this was only to 'make up numbers'. She had limited social support and income.

Sarah.

This professional woman was diagnosed as having breast cancer 6 years previously with several recurrences following her mastectomy. She had been vigorously treated with a variety of morphine based drugs having experienced great pain. Indeed at one time she was told she was not likely to live. She pulled herself through that experience and tackled her iatrogenic addiction to prescription drugs. She set up a self help group and was active and astute in its management.

Mrs Sears.

Aged 72, it was 2 years since Mrs Sears' mastectomy. Radiotherapy had been considered, but she decided against it. She attended the group as soon as she felt able after returning home. She was considering being on the committee of her group, and was a regular attendee at meetings. She managed on her pension, and was a little isolated, mainly because most of her friends had died in the last few years. She still had one pal from school days.

Sheila.

Sheila had remained in touch with two other women who had been on the ward when she had a mastectomy and radiotherapy 15 months ago. She had been in the group a year, and played an active role, particularly in visiting others. She remained on the committee despite a diagnosis of secondaries. She was well socially integrated and had an extensive family who mainly lived in or around the housing estate where she herself lived.

Sonya.

Sonya was an active member and organiser in the group, as well as a founder member. Sonya had a mastectomy 2 years previously. She put a lot of her energy into her writing, as well as the group. She came from a professional background.

Tanya.

Although 8 years after her mastectomy and radiotherapy, Tanya still had problems with lymphoedema. She had been treated privately. She was a busy professional woman, who had been in the group a few months and played no particularly active role.

Tessa.

Tessa has a mastectomy and chemotherapy some 3.6 years previously and joined the self help group soon after its inception 1 year previously. As well as being a prominent member of the group she had returned to full time employment (as a salesperson) in addition to looking after her two secondary school children. At the time of the study she has suspected secondaries in the bones of her left shoulder, and was receiving radiotherapy.

Trudy.

Treated with lumpectomy following diagnosis of breast cancer, Trudy joined the group some seven months later. She played a small role in the group organisation, and remained a quiet and dependable participant. Her husband worked in the bank.

Mrs Unsworth.

In her 60's Mrs Unsworth experienced a series of biopsies followed by partial mastectomy a year previously. She was also given chemotherapy and had very difficult 'side effects'. She had been in the group about six months, and felt that she did not play an active role. However, she was seen to be a socially able woman, who stimulated discussion at meetings. She had a wide circle of friends, and her husband was a skilled factory worker.

Ursula.

Ursula had a variety of health problems and was suffering from generalised anxiety, and bereavement reaction. She had had a mastectomy two years ago. Her husband (a clerical worker) had died a year previously, and she was struggling to deal with her two teenage daughters. She described the group as 'the one place I can go and deal with me, myself'.

Vivienne.

After a long history of breast problems it was 'almost a relief' when Vivienne was diagnosed with breast cancer and treated with a mastectomy. She was the main impetus behind the group, and played an active leader role. She was well supported by her professional husband and family.

Wilma.

Wilma's mastectomy 3 years previously had been followed 1 year later by recurrence. She had been in the group six months, attending meetings, but took no part in the group organisation. In her family both her husband and her mother had died with cancer. She was not well off for money, existing mainly on state benefit, and was also quite socially isolated.

In addition to these people who took part in the formal interviews there were many others who talked at other times to me. It is impossible to name them all. Where information from these other conversations are used in the text people are identified with a pseudonym, except in those case where their identity was not recorded.

APPENDIX III INTERVIEW : PARTICIPANT

This appendix contains a draft of the interview guide used with the people in the groups. It is split into two main sections. One deals with the experiences of diagnosis and treatment of cancer, and follows through to the second section about involvement in the group. The interview in practice covered both these areas, but not usually in that order. No particular ordering was followed, but most people seemed to find it easier to talk about getting into the group first.

Most of the interviews took place in respondents' homes, and were usually taped. On average they lasted around two hours.

PERSONAL EXPERIENCE

This section, in particular was up to the discretion of the person involved in the interview. No attempt was made to "extract" information. Indications were that people were reasonably willing to talk about their experiences.

General health previously.

First indications all was not well?

What do?

Who tell?

Medical advice straight away?

How feeling then? Physical / emotional.

Diagnosis / Assessment.

How?

Where?

When?

Possibility of cancer mentioned when?

Reaction?

Treatment decision?

Any choice?

How delivered/ offered?

Description of treatment?

Hospital experience?

Prosthesis?

When? Where? Reaction? New information since?

Reactions of others?

Family? Friends? Partner?

Initial reactions

Follow up?

Check ups? Recurrence?.....Support - Formal / informal?

Still feel like a patient?

Describe.

Personal reaction / change?

Other effects?

Relationships? Work? Family? etc

Any good points about experience?

Any criticisms?

Beliefs about causes of cancer?

How does the group fit into all this?

GROUP SECTION

Starting?

How involved?

How came to hear about group?

What think happened in group?

Was it as expected?

Contact.

Recall first contact?

Pattern of membership? meetings, phonenumber etc.

Best or most useful meetings

Other groups- contact? Check all group involvement.

Differences in the groups? aims? membership? meetings?

Still go?

Why this group?

Perception of group.

Main concern of group, of self?

What happens at meetings? Experience of meetings and other contacts

Happy with way group is going? Changes?

How feel in group? Active? passive? etc

Feel a part of group?

Contribution to group? Check all aspects of participation, talking, making tea etc.

What get out of group?

Time spent in group work?

Effect on family and friends?

Benefits

Does the group help?

How?

What's important about being in the group?

Time spent talking? sharing experiences? talking about cancer?

Main affect of being in group?

Could get that elsewhere?

Drawbacks?

Any difficulties in being in group?

To do with self, fears?

Family etc?

Difficulties concerning group?

Formal services.

Still use formal services?

Any professionals in group? What do they do? Check contacts, prompt speakers etc.

Evaluation of that. Need professional support?

Feelings about that?

Professionals realistic idea? Those professionals and others?

What idea do think they have? eg GP, consultant?

What relationship would like to see? Help from professionals? Difficulties anticipated?

Best contact?

How might this come about?

Could professionals learn from group?

Any other information?

APPENDIX IV INTERVIEW : PROFESSIONAL

This appendix contains the guide for interviewing professionals. These interviews were usually conducted in the interviewees' place of work. They were taped if possible, and commonly lasted about an hour.

Contact and Knowledge

Know of groups? In area? Other areas?

Know of cancer groups?

Check detailed knowledge of *each* group. eg. meetings, where, when, activities, phonenumber?

Contact / involvement with group? Who initiated?

Any group literature / information available?

When/ why group set up?

What does group do? What's it for?

Ever refer into group? Why? Why not?

Recommend group? Decide not to recommend?

Any feedback about referrals?

Ever approached group for information?

View of group

What relations with formal services?

Benefits and drawbacks? Note comments for members and professionals.

Need for groups of this sort? Why? Why not?

Limits? Relations to own service provision?

Why do people go to these groups?

Future

What like to see groups doing?

Best relations with self/ formal services?

Who might be involved?

Offering anything yourself?

Encourage them / not?

Any other comments?

APPENDIX V PARTICIPANT INTERVIEW - DATA (SAMPLE)

- 030 Woman went with dropped out. "Didn't want to be stuck listening about cancer"
specialist nurse.
- 009 How did you come to be involved in the group?
Flus Dr - after hospital. came back again - in her house
2/3 weeks after home
How did you hear of the group?
Wasn't first interested, didn't want to know 2-3 weeks later *TIMING
- 032 What did you think happened in the group?
No clue. Thought. If it constantly reminds of ca - Not interested
No info. ^{being out of depression really}
Was it as you expected? No.
- Can you remember the first contact you had?
6/7 then in ES house met I - etc Just starting at 3rd meeting
- Pattern of membership.
- 035 Views on partial attendance of gang people - busy lives etc
- How often do you go along to meetings? /
Most Every meeting. ← confirmed by p
- Do you ever choose not to go? Why?
009 Lazy & terrible night
033 ~~Don't~~ go. terminal cancer! depressing! Not keep fit
- What meeting(s) have you particularly enjoyed/ found useful?
All
- Other groups.
- Do you know of any other groups?
275 That's why we came to. Heard of others eg A -
Been asked to their meetings - good
Have you been to any other groups (not restricted to medical ones)?

APPENDIX VI DATA ANALYSIS SHEET (SAMPLES)

Experiences

Group B.	Tape 1	Tape 2	
1. Pre-state	038 Gyst 20 yrs ago 075 Feeling well 260 Fth. BSE	100 'queer'	
2. First	055. Sore arm swelling	080 Bath	
3. Action?	→ GP. 093 with a couple of weeks.	090 husband → GP	
4. Diagnosis	061 No mention Ca. 105 Never mentioned	086 Ca -by GP.	
5. Cancer Reaction	045 "Depressed" 067 Anaesthetic reaction	125 L--- Unit cried alot	
6. Choice?	118 * 125-too 141* stupor dopey.	087 * 157 No alternatives	
7. Treatment	mastectomy 072 'no treatment'	mastectomy.	
8. Prosthesis	142 * 150 getting another	158* Dunit wear it for years.	

* Denotes interesting quote — transcribed
into index card.

APPENDIX VI DATA ANALYSIS SHEET (SAMPLES)

Group B	Tape 1	Tape 2	
1 Start	005 Contact C number	004 Contact C member.	
2a Expectations	022 'Same boat'	011 Discuss problems	
2b Reason for going	026 'on own'		
3. First Contact	035 home visit social meet.	020 D.K. 0123. sitting talking	
4 Best meeting	Homeopathy 072 G.P.	025 'all of them'	
5 Pattern of membership	460 'not very active' visits others meeting.	330 Most meetings	
6 Participation 'within'	462 Not a committee person	046 Contact Talking to others	
7. Participation 'outside'	visits. ① Contact.	* 072 Happy to visit but don't just now Ruffe, after 041	
8. Benefits	030 helped. 370 - after coming home. info.	Prostheses 105	
9. Support?	305 Other member 0025 support.	337 Yes. seeing others.	

* Denotes interesting quote - transcribed
onto index card.

APPENDIX VII PARTICIPANT OBSERVATION NOTES (SAMPLES)

This provides an extract copied from the participant observation notes, which is transcribed below.

15 Oct. Drs. 20 Oct. Drs. + Me.

Dr S: Family? Should we be seeing them? Nurses do. How formal?

AB: Don't like that - X Prof. working - they're camp X

CD: gp get stuck, ill/death - accept that. Not heavy at all. Social - come if you want to talk.

Dr S: how get out?

AB: not everyone. Not been asked to L - but . . . called in - → staff
Been through it

Dr S: ? surgeon not seeing (pp)?

AB: GP's. imposs. Not know - feel - till had it. Conf. ang. frust. fr. Emotions?
1 yr later? Physical → emot scars. Ftf as well

CD: X cope hopelessness.

AB: too close

CD: grp talk. Family dwelling

Dr S: ? husbands → gp? Not talking. ? worried?

CD: : gp confidential or not of Problems not minor -
8/2/85 Group A

15 women, at meeting, talk between 2 women, me and Dr S.

Dr S: What about the family? Should we be seeing them? Nurses do it (sometimes). Should it be more formal?

AB: We don't work like that at all, I can't picture it working. I might be completely wrong.

CD: The group go through it, illness and death, and accept that. It's not heavy at all. It's social. (women) come if they want to talk.

Dr S: Is it a way to get out?

AB: Not for everyone. We've not been asked to (hospital), but (four consultants) have called in (member of the group) to talk to staff. Someone who has been through it.

Dr S: (Do you think) the surgeon is interested in surgery not people?

AB: (It's like at the) GP's. It's impossible. Nobody knows how you should feel if you had it - till you've had it. Confused, angry, frustrated, fear. How do you cope six months, one year later? After the physical scars heal there are emotional scars. Family and friends as well (don't understand).

CD: (They) can't cope with hopelessness) *Not clear if family or surgeon.*

AB: They're too close.

CD: (The group is) somewhere you can talk. Your family think you are dwelling on it.

AB: (response not recorded)

Dr S: (What about having) husbands in the group? Maybe they're not talking because they are worried.

AB: (Response not recorded)

CD: (The group is) confidential for women, its not for men. Problems are not immediate....

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